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Deborah Marcia Levin

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PSYCHOLOGICAL ADJUSTMENT AMONG THE PHYSICALLY
DISABLED: THE ROLE OF SOCIAL SUPPORT AND
COPING STRATEGIES



by
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Submitted in partial fulfillment
of the requirements for the degree of
Doctor of Philosophy

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Deborah Marcia Levin, 1982

ABSTRACT

Psychological adjustment is considered to be a critical component of overall adaptation to physical disability. Research has consistently shown elevated rates of psychological distress among the disabled yet factors that influence variations in psychological adjustment among the disabled have not been firmly established. This study examines the influence of two factors - social support and coping strategies - on psychological adjustment among the disabled.

Respondents for the study were obtained through a stratified multi-stage clustering technique. Screening interviews were conducted at more than 10,000 households in Southwestern Ontario, and from the screenings 1509 persons with physical disabilities were identified. Nine hundred ninety five of these persons participated in this study. The respondents had a wide array of disabilities, with varying degrees of impairment. They ranged in age from 18 - 92 years.

Disability was defined in terms of a limitation in one or more role areas because of a physical health condition. Criteria for inclusion in the study included 1) a disability duration of three months or longer or an anticipation that the disability would be of long term or

permanent duration; 2) aged 18 years or over; 3) no mental handicaps; 4) community residence, as opposed to residence in institutions for the disabled or aged; 5) ability of the respondent to personally complete the interview, which excluded persons with insufficient English language abilities or with severe speech disorders.

A series of multiple regression analyses were done to examine the relationship between social support and psychological adjustment. Social support was found to be importantly associated with psychological adjustment, independent of the effects of life events stress, age, sex and several disability related variables. The disability related variables considered made only a minimal contribution to understanding psychological adjustment among the disabled.

The relationship between coping and psychological adjustment was also examined through multiple regression procedures. Coping was weakly associated with depression and self-esteem but no significant relationship with general distress was observed. The relationship between coping and psychological adjustment was examined across problem categories and problem stress level, and, while some variations were observed, a consistent pattern could not be discerned.

The relationship between social support and coping strategies and their joint effects on psychological adjustment were also examined. Social support was found to be

more strongly associated with psychological adjustment than was coping and no significant interaction effect of social support and coping was found.

The implications of these findings for future research and intervention programs are discussed. .

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CHAPTER 1

INTRODUCTION

Disability constitutes a significant health and social problem that affects large numbers of people. The prevalence of disability in Canada or elsewhere is not known precisely; estimates tend to vary considerably, depending on definitions of disability and research methods. Data from the 1978 Canada Health Survey (Statistics Canada, 1981) indicated that 12 percent of the population experienced some limitation of activity due to chronic health conditions, including mental disorders. Another recent Canadian study estimated that in 1979 8.7 percent of the population, or two million persons, were disabled, where disability was assessed in terms of chronic disease, physical disability, or restriction in activities of daily living (Walker and McWhinnie, 1980).

Data from American studies show somewhat higher prevalence rates. Results of the 1979 Health Interview Survey (DHEW, 1981) indicated that 14.6 percent of the American population experienced activity limitations because of chronic illness. The 1972 Social Security Survey of the Disabled (Allan, 1976) found that 15.2 percent of the population was disabled, where disability was defined as a limitation in the kind or amount of work that could be

performed because of a chronic health condition or impairment. The prevalence of disability increased sharply with age. The rates increased from 7.2 percent for those between 20 and 34 years, to 19.3 percent for those between 45 and 54 years, to 29.4 percent for those between 55 and 64 years (Allan, 1976). These data indicate that physical disability represents a problem of considerable magnitude.

While there is no generally accepted definition of disability in Canada or elsewhere (Brown, 1977) there does appear to be considerable overlap in the definitions offered in the literature, suggesting the existence of some conceptual agreements. The World Health Organization defines disability as:

an existing difficulty in performing one or more activities which in accordance with a person's age, sex, and normative social role, are generally accepted as essential components of daily living, such as self-care, social relations, and economic activity. Depending in part on duration of functional limitation, disability may be short-term, long-term or permanent (WHO, 1976).

Haber (1967) defines disability as a "loss or decrease in the ability to respond to behavioral expectations as a result of impairment and functional limitations." Similar definitions are offered by Reusch (1969), Nagi (1976) and Albrecht (1981).

The developmental sequence of disability is portrayed in a model developed by Wood (1975) and adopted by the World Health Organization (WHO, 1976). The factors

involved in this process include disease, impairment, and functional limitation. Basically the model shows that disability begins with chronic illness that may or may not result in impairment. Given impairment there may or may not be some functional limitation and the presence of functional limitation may or may not result in disability.

The present study focuses on persons who have identified themselves as disabled by some medical condition, on the basis of some limitations in one or more role areas. The specific definition of disability to be used in this study will be discussed in detail in a later section. Given that disability is defined in terms of restrictions in normal roles and activities, disability can be seen to have important consequences for an individual beyond those of a purely physical nature. The disabled individual may face the loss of key social and vocational roles, disruption of present lifestyle, and erosion of plans for the future. Physical disability also represents a significant assault on psychological well-being. A conception of oneself that is based on a healthy body and participation in particular roles and activities may no longer be valid, yet this cannot be easily or immediately replaced by a new self-conception that integrates the physical disability.

In recognition that many spheres of life may be affected by physical disability, it is widely agreed that adaptation among the disabled must be evaluated in terms of two distinct dimensions: physical function and

4
psychological function (c.f., Albrecht and Higgins; 1977; Safilios-Rothschild, 1970). It has been stated that:

Rehabilitation is a life-long task. The physical rehabilitation process, although extremely important, is relatively short. People usually achieve maximum physical recovery within one year. Psychological adjustment comes more slowly and more painfully (Vargo, 1978:34).

The purpose of this study is to evaluate psychological adjustment among persons with physical disabilities, and to assess the influence of social support and coping strategies on psychological adjustment. There are no standard criteria for what constitutes successful psychological adjustment among the disabled. Because of the nature of physical disability an individual may have to restrict the range of his activities and relinquish certain goals. White (1974:52) has conceptualized the adaptive process as a "striving toward an acceptable compromise." Hamburg and Adams (1967:278) discuss successful adaptation in terms of "keeping distress within manageable limits; maintaining a sense of personal worth; restoring relations with significant other people, and increasing the likelihood of working out a personally valued and socially acceptable situation after maximum physical recovery has been obtained."

The work of White (1974) and Hamburg and Adams (1967) provides the conceptual framework for adjustment as it is employed in this study. Psychological adjustment is

assessed in terms of self-esteem and freedom from various dimensions of psychological distress including anxiety, anger/aggression and depression.

The central objectives of this study are:

- 1) to examine the impact of social support on psychological adjustment among the disabled;
- 2) to examine the influence of coping strategies on psychological adjustment among the disabled;
- 3) to examine the interaction of social support and coping strategies and their combined effects on psychological adjustment among the disabled.

Both social support and coping strategies have been shown to have an important impact on psychological health status among normal populations. The influence of these variables on psychological health status among disabled populations has not been well investigated, and an understanding of the role of these variables in a disabled population may have significant implications for rehabilitation. Social support and coping strategies are both likely to be malleable and thus could be useful targets for intervention programs aimed at enhancing psychological adjustment among the disabled. However, prior to the utilization of these variables in such intervention, increased knowledge of their impact on psychological adjustment among the disabled is needed. This study

represents one effort to provide such information.

In Chapter Two, earlier research on the psychological health status of the disabled is reviewed. Chapter Three provides a review of the social support literature, and the coping literature is examined in Chapter Four. In Chapter Five the research methods of this study are presented. Together these chapters provide the theoretical, substantive and methodological context in which this study is grounded.

CHAPTER 2

PSYCHOLOGICAL ADJUSTMENT AMONG THE DISABLED: REVIEW OF THE LITERATURE

2.1. Psychological Adjustment Among the Disabled

The changes in lifestyle that may ensue from physical disability, and the assault on bodily integrity common to all persons with physical disability, are thought to produce significant consequences for emotional well-being.

Several studies have compared the psychological health status of disabled and non-disabled populations. Many studies have reported that the physically disabled are significantly more depressed, anxious, and lower in self-esteem, and display more neuroticism than normals (Earle et al., 1979; Gardiner, 1980; Kasl and Cobb, 1969; Polley et al., 1970; Rosenbaum and Raz, 1977; Rutter, 1977; Shaffer et al., 1972).

Rutter (1977) compared thirty persons with chronic bronchitis with thirty matched healthy controls. Patients obtained significantly higher scores on the Zung Depression Scale (1965) and Goldberg's General Health Questionnaire (1972). According to Goldberg's criteria for a probable psychiatric case, 48 percent of the bronchitics were probable cases compared with 13 percent of the controls.

Several studies have examined psychological distress among rheumatoid arthritics. Gardiner (1980) compared the scores of a group of rheumatoid arthritics with normative data on the Eysenck Personality Inventory (1974), The Zung

Depression Scale (1965) and the Goldberg General Health Questionnaire (1972). It was found that the arthritics were significantly more neurotic and more depressed than normals. Using Goldberg's criteria for a probable psychiatric case 53 percent of the arthritics were probable cases.

In a study by Crown and Crown (1973) the psychological health status of newly diagnosed rheumatoid arthritics was compared with groups of neurotic and normal controls. The arthritics were significantly less disturbed than the neurotic controls on all measures of psychological well-being except for anxiety and there were no significant differences between the arthritics and the normal controls, again, except for the anxiety measure. The authors conclude that early arthritics resemble the normal population and are strongly differentiated from the neurotic population.

Ward (1971) compared a group of rheumatoid arthritics who were less than one year post-onset, a group of rheumatoid arthritics who were at least 5 years post-onset, a group of neurotics from a general psychiatric practice, and a group of normal controls. Both the neurotic and the normal controls had significantly higher mean neuroticism scores than either group of arthritics and the chronic arthritics had lower neuroticism scores than the early arthritics. The author concludes that arthritics do differ significantly in personality from both neurotic and normal

populations. He suggests that arthritics substitute physical symptoms for neuroses. That the differences between the arthritics and control groups were greatest among the chronic arthritics is seen to indicate that these personality differences develop as a result of the disease, and are not apparent premorbidly.

The notion that there is a chronic disease personality was examined by Spergel et al. (1978). Persons with rheumatoid arthritis, gastric ulcers, low back pain, and multiple sclerosis were compared on the MMPI and the Tennessee Self Concept Scale. The MMPI profiles of each group differed from those of normal subjects but they did not differ significantly from one another. All the disabled were moderately depressed, and on the Tennessee Self Concept Scale all groups scored low in body image but otherwise were not low in self-esteem. The authors interpret the results as suggesting that there may be a chronic disease personality, although the data do not support a specific disease/specific personality relationship.

A number of other studies have compared the psychological health status of persons with various disabilities. Using the MMPI, Bourestom and Howard (1965) examined the personality characteristics of persons with rheumatoid arthritis, multiple sclerosis and spinal cord injury. Those with spinal cord injuries appeared to be the best adjusted, with fewer emotional problems than those with multiple sclerosis or arthritis.

The MMPI was used by DeConcio et al. (1968) to assess the adjustment of persons with emphysema and they were compared with the adjustment of persons with spinal cord injury, rheumatoid arthritis, and multiple sclerosis. Persons with emphysema scored significantly higher than normals on all scales of the MMPI and this was most pronounced in the neurotic triad of depression, hypochondriasis and hysteria. Persons with emphysema were less neurotic than those with rheumatoid arthritis or multiple sclerosis but were less well adjusted than those with spinal cord injuries.

Nelson and Gruver (1978) examined psychological well-being among a group of hospitalized spinal cord-injury patients, hospitalized tuberculosis patients and non-hospitalized normals. No significant differences were found on any of the 24 factors measuring psychological well-being between the spinal cord injury group and the normals. The tuberculosis group was significantly more anxious and had lower self-esteem than either the spinal cord injury group or normals. The authors suggest the low self-esteem of the tuberculosis group was related to the stigma of tuberculosis as a dirty disease.

Other studies that have assessed the psychological health status of persons with physical disabilities, but have not used comparison groups, have produced contradictory results. Vignos et al. (1972) studied rheumatoid arthritics who had had the disease for at least one year.

Psychological adjustment was based on assessment by psychologists taken at the start of the study and one year later. Approximately 50 percent were judged as personally well-adjusted initially, and there was little change after one year.

Stern et al. (1976) studied survivors of acute myocardial infarction and found that at a one year follow-up only 20 percent of the survivors exhibited significant depression or anxiety, as measured by the Zung Depression Scale, and the Taylor Manifest Anxiety Scale.

Isaacs et al. (1976) did a three-year follow up of 29 stroke patients and found that depression and aggression were common. However this conclusion was based on personal observations and impressions, rather than on empirical measurement. The findings of this study are however, consistent with other impressionistic studies that have reported substantial psychological maladjustment among those with physical disabilities (Abram, 1972; Charaton and Fisk, 1978; Geis, 1972; Reiner, 1975; Siller, 1969; Simon, 1971).

This review has reported generally consistent findings of elevated levels of psychological distress among the physically disabled. However many of the studies were beset by methodological shortcomings. Sample sizes were frequently small and significance tests were often not reported. Disabled subjects were frequently not representative, and thus often constituted select groups from physicians'

practices and specialized treatment facilities. Further research on the psychological health status of the physically disabled will be improved by representative samples and larger sample sizes.

2.2. Severity of Disability and Psychological Adjustment

If physical disability is seen to have a negative impact on one's psychological health status it would seem to follow that the more severely disabled would be more psychologically distressed than the less severely disabled. A number of studies have examined the relationships between severity of disability, assessed through either the severity of the physical impairment itself, or through degree of functional incapacitation, and various indicators of psychological adjustment. Two hypotheses relevant to the relationship between the severity of disability and psychological health status are evident in the literature (c.f., Colman, 1971; Skipper et al., 1968; Thomas, 1966; Zahn, 1973). The social rejection hypothesis suggests that the psychological distress experienced by the disabled stems from their perception that people react negatively toward them and reject them socially. Alternately, the role conflict hypothesis suggests that psychological distress is occasioned by the increased role ambiguity experienced by the disabled individual. In many situations the disabled individual's view of himself as disabled or normal may not correspond with others' conception of him in that given

situation, thereby generating uncertainty and psychological distress.

In a test of the role conflict versus social rejection hypotheses, Colman (1971) compared persons with orthopedic disabilities who were rated as either severely or moderately impaired. The more severely impaired showed significantly greater adjustment on a measure of self-acceptance and neuroticism when compared with the moderately impaired. Colman suggests that the greater psychological distress manifested by the moderately impaired stems from the greater role conflict they experience. Zahn (1973) also indicated that when the severity of impairment is unclear to others greater interpersonal problems occur. In this study severity of disability was assessed in terms of ability to work and sexual functioning. In a group of persons with diverse disabilities, the more severely disabled were found to have better interpersonal relations than the less severely disabled. Better interpersonal relations with friends and casual acquaintances were associated with fitness to work, but among family, those not fit to work had better interpersonal relations. Similarly those who were sexually impaired had better relationships with their spouses and experienced less disruption in general family relations than those who were not. The only finding contrary to the pattern of better interpersonal relations among the more severely disabled concerned the visibility of the impairment,

defined by the presence of equipment for ambulation or muscular control. Visibility of impairment was very disruptive of both family and secondary relationships. Zahn (1973) suggests that the clarity of status experienced by the more severely disabled may lead to a greater degree of self-acceptance and subsequently of acceptance by others.

Several additional studies have assessed the relationship between severity of the impairment and psychological adjustment. Stern et al. (1976) reported that the severity of initial myocardial infarction did not differentiate between the poor rehabilitation group who were depressed, anxious and had a lower rate of return to work and sexual functioning than the good responders at successive interviews up to a one-year follow-up. Earle et al. (1979) reported that severity of rheumatoid arthritis was significantly related to self-esteem and feelings of meaninglessness, but Vignos et al. (1972) and Gardiner (1980) have reported no significant relationship between these variables. However Vignos et al. (1972) did find that maintenance and improvement in activities of daily living over the one year study period was significantly related to better social adjustment.

Similar results were reported by Fishman and Petty (1971) who found that, over a one year period, improvement in objective measures of impairment and physical symptoms experienced by 30 chronic bronchitis and emphysema patients

was significantly associated with improved psychological adjustment.

Other studies of the relationship between functional status and psychological adjustment have produced contradictory results. Albrecht and Higgins (1977) and Crown and Crown (1973) reported that level of physical functioning was not significantly related to measures of psychological adjustment, while Alexander et al. (1979) found greater emotional distress among the more severely impaired.

Braham et al. (1975) assessed the needs of persons with multiple sclerosis living in the community, and found that even subjects with low disability ratings and high independence in activities of daily living had many unmet needs. Foremost among these was the individual's reaction to his illness. Subjects felt they needed help in accepting the illness, in dealing with depression, handling dependence on others, concern with role changes and expression of suicidal thoughts.

In a study of 141 persons with diverse disabilities (Smits, 1974) level of physical functioning was not significantly related to social relationships, participation in the family, or independent outlook but was significantly related to a measure of affective outlook. The author suggests that while treatment efforts directed at improved physical functioning may have a definite impact on certain desired outcomes, such as self-care and employability, the generalization effect will be limited and psychosocial

problems may remain unsolved.

Susset et al. (1979) studied over 500 persons with diverse disabilities and found that, for the entire population, there was a significant correlation between scores on the physical function index and the psychosocial index. However, for specific subgroups, there were lower correlations between the two indices. Paraplegics and quadriplegics achieved high psychosocial scores despite less physical function than the other subgroups. Persons with cerebrovascular accidents, hemiplegias, multiple sclerosis, arthritis and lower limb amputations scored low on the psychosocial index, compared with their scores on the physical index. The authors suggest these subgroup differences were due in part to the younger age, the more frequent availability of a supportive family, and more frequent rehabilitation care among the paraplegic and quadriplegic groups. The results of this study indicate that, in assessing the influence of severity of disability on psychosocial outcome, other contributing factors need to be controlled.

In sum, three studies (Colman, 1971; Fishman and Petty, 1971; Zahn, 1973) have reported that severity of impairment or functional status is negatively correlated with psychological distress, three studies have reported a positive association between these variables (Alexander et al., 1979; Earle et al., 1979; Smits, 1974) and five studies have found no significant relationship (Albrecht

and Higgins, 1977; Crown and Crown, 1973; Gardiner 1980; Stern et al., 1976; Vignos et al., 1972). A study by Susset et al. (1979) has suggested that the relationship between severity of impairment and psychosocial functioning is likely to be influenced by other factors.

Thus these studies indicate, with a few exceptions, that there is not a direct relationship between severity of impairment or functional status, variously measured, and psychological adjustment. It appears that factors other than the severity of the physical disability have a greater impact on psychological adjustment among the disabled.

2.2.1. Summary. This review has illustrated the uncertain nature of psychological health status among the disabled. The majority of research suggests that persons with physical disabilities tend to have elevated levels of depression and anxiety, and low self-esteem. Further, it appears that psychological well-being among the disabled is not clearly related to type of disability, severity of impairment or degree of physical function limitations.

Further progress in understanding important variations in psychological adjustment among the physically disabled requires a new research approach. There is a large body of literature on the correlates of psychological well-being in the general population and examination of those factors that have been shown to have important effects on the psychological well-being of the non-disabled provides a good starting point for further research on

psychological adjustment among the disabled. This study examines the influence on psychological adjustment of two particularly important factors - social support and coping strategies.

In the following section the association between social support and psychological adjustment among the disabled will be examined. The particular importance of this variable in the study of psychological adjustment among the disabled will also be discussed.

2.3. Social Relations and Psychological Adjustment Among the Disabled

There is considerable evidence to suggest that the presence of physical disability can have important consequences for interpersonal relations. This is true for family relationships, friendships, and more distant relationships. Data from the American Social Security Administration Survey of the Disabled (Franklin, 1977) showed significantly higher rates of divorce among married couples with a disabled partner. O'Brien (1980) found that among a group of hemodialysis patients there was a large increase in the amount of interactional behavior with family members but there was also a significant decrease in the quality of such interaction. Carlson (1979) found that among a group of paraplegics and quadraplegics dissatisfaction with life was frequently greatest in family and other intimate relationships.

Physical disabilities that result in communication problems or are highly visible such that they require the use of equipment for ambulation or muscle control, have been found to be particularly damaging to relations with both family and friends (Zahn, 1973). There is some evidence to suggest that the disabled are rejected as friendship choices (Ingwell et al., 1967), and that in interactions with the disabled, able-bodied individuals feel uncomfortable and inhibited (Comer and Piliavin, 1975; Kleck, 1966; Kleck et al., 1966).

These findings are congruent with the notion that the physically disabled constitute a socially stigmatized group (Goffman, 1963) and their interactions with non-disabled persons are colored by this stigma (Chaiklin and Warfield, 1973; Cogswell, 1968). On the other hand Earle et al. (1979) found no significant differences in perceptions of family appreciation or feelings of loneliness/isolation in a comparison of rheumatoid arthritics and normals and West (1977) found that cancer patients with facial disfigurements felt that in general people treated them no differently than before surgery, although some staring, avoidance and mistreatment did occur.

Nonetheless, it appears that disability frequently has an adverse impact on interpersonal relations. At the same time interpersonal relations, particularly with family members, may have important implications for psychological adjustment among the disabled. As Versluys (1980) has

stated "the family's response to the injured/ill person may determine the patient's motivation to tolerate painful procedures and long-term treatment, to face irrevocable losses, and to accept major lifestyle changes."

Several studies have shown that social support facilitates good psychological adjustment among the ill and disabled (Davidson et al., 1981; Dimond, 1979; Jamison et al., 1978; Kemp and Vash, 1971; Lesser and Watt, 1978; Robertson and Suin, 1968; Smits, 1974; Susset et al., 1979). However the measurement of support in these studies has frequently been weak, and often non-existent. Susset et al. (1979) reported high psychological scores were more frequent among those who "had a family able to provide a useful support for their motivation." However there was no indication of how family support was measured. Smits (1974) simply stated that an individual who had a good psychosocial outcome was a "member of a close family unit which responded appropriately to his disability, for example, helped him to function with as much independence as possible."

Two studies utilized more elaborate measures of support. Davidson et al. (1981) assessed support in terms of love, esteem and a sense of reliable alliance the person experienced from family, friends and peers. A significant relationship between overall social support and self-esteem was found across the total sample of burn-injured patients, although this relationship was strongest among the most

severely burned patients. This was also true for friend and peer support. Family support was strongly associated with self-esteem, and this did not vary with severity of burn-injury. A different pattern characterized the relationship between social support and life satisfaction. Among the moderate burn-injury group only family support was significantly related to life satisfaction. However, among the severely and critically burned patients social support from all sources was significantly related to life satisfaction.

Dimond (1979) examined the influence of support on morale and social functioning among hemodialysis patients. Patients rated support from their families in terms of family cohesion - helpfulness and supportiveness of family members, and family expressiveness - the extent to which open expression of feelings is encouraged. The availability of a confidant was also assessed, and the supportiveness of spouses was rated through nurses' observations of their sensitivity, encouragement, and availability. All four measures of support were significantly related to morale, with family expressiveness showing the strongest relationship. Family cohesiveness and availability of a confidant were both significantly related to fewer changes in social functioning since the onset of dialysis.

The studies reviewed here suggest the importance of the social support variable in the study of psychological

adjustment among the disabled. There is a clear need for further research on psychological adjustment among the disabled that includes valid and reliable measures of social support. A large body of research on social support and psychological health status among non-disabled populations indicates that social support is importantly associated with psychological well-being. In Chapter Three a review of the social support literature will be presented in order to illustrate this relationship and demonstrate its potential significance for enhancing our understanding of psychological adjustment among the disabled.

CHAPTER 3

SOCIAL SUPPORT

3.1. Introduction

The study of social support derives from the view that "people's relation to their social environment has a critical influence on their health" (Gottlieb, 1981:16). This literature review will focus on three central approaches to the study of social support: social integration; social networks; and the social-psychological perspective of social support.

The conceptualization of social support as expressed by each of these approaches will be discussed, and evidence on the relationship between social support and health status that has been guided by each of these approaches will be examined.

A majority of studies on the relationship between social support and psychological distress have employed a cross-sectional design. It is difficult to disentangle cause and effect relationships within cross-sectional studies, and thus there is at present little evidence on the causal direction of the social support/psychological distress relationship. The issue of causality will be discussed further at the end of this chapter.

3.2. The Social Integration Approach

The social integration approach examines support in terms of connections with society, through both primary and secondary relationships and informal and formal group associations. A number of studies have shown higher rates of psychiatric disorder among persons who were less well-integrated into society. Myers et al. (1975) found that in a community sample, persons who had experienced high levels of life stress in the past year yet experienced few psychiatric symptoms at the time of the study were more highly integrated than those who had experienced low levels of life stress and many psychiatric symptoms. The authors suggest that persons who have "ready and meaningful access to others, feel integrated into the system, and are satisfied with their roles seem better able to cope with the impact of life events." Berkman and Syme (1979), in a retrospective study, assessed the impact of marital status, contacts with close friends and relatives, church membership, and informal and formal group associations on risk of mortality among more than 6,000 adults over a 9 year period. Each of these four measures was independently associated with risk of mortality. Marital status showed the strongest association, with significantly lower rates of mortality among the married for all age and sex groups. Brown et al. (1979) reported that the less socially integrated women in an island community had higher rates of depression than the more socially integrated women.

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Integration was determined by whether the woman grew up on the island, lived in a household engaged in one of the two major economic/occupational activities of the island, and went to church regularly. Other studies have also produced evidence to demonstrate a significant relationship between these variables (c.f., Eaton, 1978; Lin et al., 1979a).

3.3. Social Networks

The social network approach shares some characteristics with the social integration approach. The differences between these approaches have been succinctly stated by Mitchell and Trickett (1980:28): "Although social support systems are often thought of in terms of some formally recognized entity (i.e.; family, neighbourhood, church, or social organizations...) it is often some unique configuration of these that comprises the salient reference group of the individual. The concept of social network presents one way of getting across these formal boundaries and examining the total social field within which the individual is embedded."

Social networks generally refer to the interpersonal linkages among a set of individuals. Research on social networks has frequently analyzed networks in terms of specific structural characteristics. Those characteristics most commonly surveyed include: 1) size: the number of people in the network; 2) density: the extent to which individuals within a network know and contact one another

independently of the focal individual; 3) multiplexity: the extent to which relationships cross more than one content area, such as work, friendship, recreation; 4) directionality: the extent to which relationships are reciprocal rather than in one direction only.

There is evidence from several cross-sectional studies to indicate that variable types of social networks are associated with differential psychological well-being. Hammer et al. (1978) reported that among a general population sample the primary network usually consists of 25-40 people and of these, 6-10 are known intimately. Within the social network there are typically several clusters with 6 or 7 highly interconnected individuals in each cluster. A similar network pattern among normals was reported by Pattison et al. (1975). However, these researchers found different patterns among neurotics and psychotics. Primary networks of neurotics were smaller than those of normals (10-12 people) and often included significant persons who were no longer living or lived far away, and there was a low level of interconnectedness among members. Interpersonal relations with network members were more often rated negatively by neurotics than by normals. In their study of the social networks of neurotics and normals Henderson et al. (1978) also found smaller networks and greater negative interaction among the neurotics.

The social networks of psychotics appear to be clearly differentiated from those of both neurotics and

normals (Sokolovsky et al., 1978; Tolsdorf, 1976; Pattison et al., 1975). The networks of psychotics are characterized by their small size, domination by kin, and the large proportion of dependent relationships.

An interesting finding is that the psychiatric populations expressed less satisfaction with their social network relations than did non-psychiatric populations (Henderson et al., 1978; Pattison et al., 1975). Henderson et al. (1978) found that the neurotics and controls did not differ significantly in amount of positive interaction but had substantially more neutral and negative interaction. This suggests that the quality of social relations and what people gain or do not gain from their social relations may have important consequences for mental health. Pearlin et al. (1981:11) have stated "...being embedded in a network is only the first step toward having access to support; the final step depends on the quality of the relations one is able to find within the network." In the next section the social-psychological approach to social support, which focuses on the psychological content of social support, and implicitly on the quality of support, will be examined.

3.4. The Social-Psychological Approach

The social-psychological approach focuses on what Henderson (1980) has termed the "affectional content and psychological function" of social networks. The conceptualization of social support as expressed through

this perspective is exemplified in the work of Cobb (1976) and Weiss (1974).

Cobb (1976) has viewed social support as comprised entirely of information. Specifically he conceives it to be information belonging to one or more of the following three classes: 1) information leading the subject to believe that he is cared for and loved; 2) information leading the subject to believe that he is esteemed and valued; 3) information leading the subject to believe that he belongs to a network of communication and mutual obligation.

This conceptualization shares much with the "provisions of social relationships" described by Weiss (1974). Weiss proposes six categories of these provisions, each generally associated with a particular type of relationship. These are: 1) a sense of attachment and belonging, often provided by marriage or other cross-sex relationships; 2) social integration, provided by a network of friends and colleagues who offer companionship and opportunity to share interests and values; 3) opportunity for nurturing others, most often children, which provides a sense of being needed; 4) reassurance of worth provided by family, friends and colleagues who attest to an individual's competence in a given role; 5) the opportunity for the obtaining of guidance by trustworthy and supportive friends and relatives; 6) reliable alliance, provided by kin.

These conceptualizations share a focus on the individual's experience of being supported, and on those psychological gains intrinsic to support. A focus on what it is that an individual derives from social support may provide significant insight into the ways in which social support comes to influence psychological well-being.

Within the social-psychological approach, support has been examined from a variety of perspectives. A confiding relationship, in which people can talk intimately about themselves or their problems, has been shown to be crucial for good psychological health status in several studies. Brown et al. (1975), in a retrospective study, examined the influence of a confidant in reducing the risk of depression following a major life event or long term difficulty. Among those women who lacked a confiding relationship with a husband or boyfriend, 38 percent developed depression following life stress or major difficulties, compared with only 4 percent of women with such a confiding relationship. A study among the elderly by Lowenthal and Haven (1968) found that the availability of a confidant offered strong protection against depression following the gradual decrease in social roles and social interaction as well as against the more sudden losses of retirement and widowhood. A beneficial effect for those with a confidant has also been reported by Miller and Ingham (1976) and Roy (1978).

Davidson et al. (1981), in their study of the

influence of social support on post-burn adjustment, developed a measure of social support grounded in Cobb's (1976) conceptualization. This measure assessed feelings of love, happiness, and acceptance, and a sense of reliance that are obtained from family, friends, and peers. A total support score, derived from a combined measure of family, friends and peer support, was significantly related to various adjustment measures, including self-esteem and life satisfaction. Family support was more strongly correlated with self-esteem, life satisfaction and social/recreational activities than was friend support, which was in turn, more strongly related than peer support. The overall social support scale was highly reliable, as were each of the subscales for family, friend, and peer support. However it is difficult to observe the components of social support that Cobb (1976) suggests are important within this scale.

Turner (1981) also employed a measure of social support based on Cobb's conceptualization. An adaptation of a measure developed by Anne Kaplan (1977) a student of Sidney Cobb's, that was designed to assess love, esteem and network support, was used in four studies with diverse populations. Across all four studies a moderate association between levels of social support and psychological well-being was found. The Kaplan Scale proved to be highly reliable but the three subscales were not distinguishable.

It seems clear from these studies that the affectional, psychological aspects of social support are

importantly associated with psychological well-being. Further specification of the underlying dimensions of social support is likely to substantially enhance present understanding of what it is about social support that matters for mental health. Such specification may indicate particular aspects of support that are especially relevant for mental health, the presence of which is beneficial and whose absence is deleterious.

Several recent studies have attempted to specify and measure various dimensions of support. Hirsch (1980) developed a measure to categorize different types of support, and assessed their relationship to measures of mood, self-esteem and psychiatric symptomatology among a group of women experiencing major life changes. Five types of support were assessed: 1) cognitive guidance; 2) social reinforcement, defined as praise or criticism regarding specific actions; 3) tangible assistance; 4) emotional support, defined as an interaction that made one feel better or worse when one had already been feeling upset; 5) socializing. Subjects completed a diary of daily interaction with network members. For each network member, subjects rated their satisfaction with each of the five types of support received. A mean daily satisfaction rating was calculated for each type of support.

Greater satisfaction with cognitive guidance was associated with better mood and less symptomatology. Satisfaction with socializing experiences was associated

with higher self-esteem. No other dimension of support attained a significant relationship with mental health.

Dean and his colleagues (Dean et al., 1981; Lin et al., 1979b) have developed a social support scale that assesses what they have termed the instrumental and expressive dimensions of support. The instrumental system is directed towards the completion of tasks, and the expressive system is concerned with the satisfaction of individual needs. The instrumental support dimension consists of two subdimensions: monetary problems and demands. The expressive dimension is comprised of three subdimensions: lack of companionship, communication problems and not having children. The total scale comprises 26 items, and respondents are asked to indicate how often they have been bothered by these problems over the last 12 months. In a study of a large general population sample (Dean et al., 1981) all the instrumental-expressive support subdimensions, with the exception of no children, were significantly associated with depression. Monetary problems and demands were more strongly correlated with depression than either lack of companions or communication problems. The combined social support indicators (this scale and several other measures) accounted for 29.3 per cent of the variance in depression.

While the results of this study appear to provide convincing evidence for the influence of social support on depression, the validity of this social support scale is

questionable. It can be argued that this scale confounds support with other variables. Monetary problems may be seen as an indicator of stress, rather than as a dimension of support. Communication problems, a subscale of the expressive dimension, is assessed through items such as unsatisfying job, no one to understand the problems, and conflicts with those who are close. While an unsatisfying job may be seen as a stressor, the extent to which this item measures lack of support, or is in the same conceptual domain as no one to understand problems is questionable.

However, despite some uncertainty concerning the validity of this instrument, its development does represent an attempt to explicate the underlying dimensions of social support and it is through further research in this direction that future progress in determining what it is about social support that matters for mental health will be made.

Henderson and his colleagues (Henderson et al., 1980a) developed the Interview Schedule for Social Interaction (ISSI) and have used this scale in a series of studies. The ISSI was strongly influenced by Weiss's (1974) conceptualization, and the items were designed to tap the availability and adequacy of the provisions of social relations suggested by Weiss. Within the ISSI, four main areas can be discerned: 1) availability of attachment, where attachment refers to an attribute of relationships which is characterized by affection and which gives the recipient a subjective sense of closeness; 2)

adequacy of attachment in terms of whether the respondent was satisfied with his attachment relationships or wanted more or less attachment; 3) availability of social integration, where social integration refers to acquaintanceships, friendships, reassurance of worth and reliable alliance; 4) adequacy of social integration. The ISSI was employed in a large general population survey of the prevalence of non-psychotic psychiatric morbidity (Henderson et al., 1980b). Availability and adequacy of both attachment and social integration were significantly related to neurosis and depression among women although among men only adequacy of attachment and social integration were significantly related to either neurosis or depression. Among women social integration had a stronger association with neuroses than did attachment but for both men and women attachment was more strongly related to depression than was social integration. Degree of unpleasant interaction accounted for considerable amounts of the variance in outcome, consistent with the findings of Henderson et al. (1978).

The development of the ISSI represents a significant advancement in the measurement of individual's social environments and their relationships within them. It provides for specification of various dimensions of social relationships, and it clearly differentiates between the availability of support and the adequacy of that support. Future progress in determining what elements of social

relations are particularly relevant for mental health is dependent on the application of measures such as this, and the work of Henderson et al. (1980a, 1980b) represents an important start towards specification of these elements.

3.5. Life Events Stress, Social Support and Health Status

As this review has illustrated, a large number of studies that have approached social support from various perspectives have consistently demonstrated a significant relationship between social support and psychological health status. How social support influences health status is not clear. There is some debate as to whether social support exerts its protective effect against psychological distress by serving as buffer against life events stress or whether social support is independently associated with psychological health status (c.f., Dohrenwend and Dohrenwend, 1978; Henderson, 1980; Thoits, 1981). Some research suggests that social support serves primarily as a buffer or mediator of the effects of life events stress (Brown et al., 1975; Brown and Harris, 1978; De Arango et al., 1973; Dean and Lin, 1977; Gore, 1978; Nuckolls et al., 1972; Pearlin et al., 1981; Walker et al., 1977). However other studies have provided evidence to suggest that social support is important for psychological health status independent of stress level (Andrews et al., 1978; Dean et al., 1981; Henderson et al., 1978; Miller and Ingham, 1976; Williams et al., 1981) and that social support has both

important main effects and buffering effects (Henderson et al., 1980b; Turner, 1981).

The recent work of Pearlin et al. (1981) provides an exciting new approach to understanding how social support influences psychological well-being. They suggest that "events do not necessarily impact upon people directly but may, instead, exert their effects through a wider context of life strains...life events may create or intensify the strains that people experience in different social roles and it is these intensified strains, in turn, which eventuate in stress." Pearlin et al. (1981) report that both social support and coping mediate in the stress-distress process, in part by reducing chronic strains that can occur following a life event, and in part by preventing loss of self-esteem and a sense of mastery that chronic strains and life events may produce, and through this effect on self-concept, influence the risk of depression.

The work of Pearlin et al. (1981) suggests an intriguing approach for research on psychological adjustment among the disabled. By virtue of their physical disabilities, they constitute a population that does experience chronic strains. Research suggests that many of the disabled do have lower self-esteem than the able-bodied. Investigation of life events, chronic strains, self-esteem, social support and coping among the disabled may enhance our understanding of both how social support exerts its influence, and of the determinants of psychological

adjustment among the disabled.

3.6. The Issue of Causality

As this review has illustrated, there is compelling evidence for an association between social support and psychological well-being. However the causal direction of this association has not been firmly established. While a number of investigators have suggested that future research be directed toward examining the issue of causality (c.f., Gore, 1981; Thoits, 1981) to date there has been little work on this.

Some evidence related to the issue of causality has been presented by Turner, Frankel and Levin (in press). They noted that "the perception of being loved and esteemed and able to count on others must be an integral part of emotional well-being, at least when broadly conceived" and thus the question of possible redundancy between measures of social support and those of psychological distress arises. Using data from four studies they examined whether the two constructs could be empirically differentiated. Each major social support index was paired with the psychological distress measures utilized in each of the studies. Factor analyses, with two orthogonal factors specified, showed that in virtually all instances, the social support items and the psychological distress items clearly loaded on different factors. The authors suggest that while experienced social support cannot be completely

separated from the general domain of psychological well-being, social support is clearly a distinct construct.

Turner, Frankel and Levin (in press) have stated:

Our consideration of the causation that may be involved in this association [between social support and psychological well-being] is guided by the view that neither social development nor functioning is very likely to proceed in terms of linear or clear-cut causes and effects. Surely, to a substantial extent and in a substantial number of social-psychological arenas, both causes and effects are reciprocal. We are persuaded by Brewster Smith's (1968:277)... view of causation in personal and social development as 'inherently circular or spiral, rather than linear, in terms of neatly isolable causes and effects'.

Turner (1981) focused more directly on the issue of causality in a study of social support and mothers' adaptation to the parenting role. Measures of psychological well-being and social support among the mothers were obtained in two interviews separated by six months. Stepwise regression analyses were applied to alternative orderings of these variables and difference in R^2 tests were employed. Turner (1981) concludes from these analyses that "some important part of the association between these variables goes from social support to psychological well-being and that some important part also goes in the opposite direction." Thus it is likely that the availability, use, and experience of social support has consequences for one's psychological health status. It is also likely that one's psychological health status will influence the

availability of social support and one's tendency to experience that support. While Turner's results clearly do not resolve the issue of causality they support the hypothesis that social support matters for emotional health and well-being.

3.7. Summary

Social support has been shown to be associated with psychological health status in a variety of contexts. Whether social support is associated directly with psychological health status or primarily as a buffer against the effects of life stress is not clear.

The study of social support among the disabled may make a significant contribution to our understanding of factors that influence their psychological adjustment. Physical disability may be a threat to social interaction with family and secondary associates. Thus while the physically disabled may have an especially great need for social support, obtaining support may be particularly problematic for them.

This study will assess social support from a social-psychological perspective, and will provide an opportunity to reliably assess social support and its influence on psychological adjustment among the disabled.

CHAPTER 4

COPING

4.1. Introduction

Antonovsky (1979) has referred to coping as a generalized resistance resource, a "resource that an individual can employ to deal with environmental and internal demands and stresses." Meichenbaum and Turk (1981) have stated "Since physical and environmental demands are ubiquitous, that which distinguishes individuals is their ability to cope. It is the nature of the coping process and not the demands per se that will determine the occurrence and extent of disease." It may be that the coping strategies employed by the disabled have important consequences for their psychological adjustment. This study assesses the influence on psychological adjustment of coping strategies that the disabled use to deal with problems that arise from their disability.

There are many definitions of coping, some of which refer to coping in general, while others are specific to coping with illness. Mechanic (1968) has stated that "coping is the instrumental behavior and problem solving capacity of persons in meeting life demands and goals." Pearlin and Schooler (1978) define coping as "any response to external life strains that serves to prevent, avoid, or control emotional distress." Lazarus and Launier (1978)

have stated that coping is the cognitive and behavioral efforts made to manage environmental and internal demands, and conflicts among them, which tax or exceed a person's resources. Lipowski (1970) has stated that "coping is all cognitive and motor activities which a sick person employs to preserve bodily and psychic integrity, to recover reversibly impaired function and compensate to the limit for any irreversible impairment." In many of these definitions coping is viewed as a response, where the response can be either a behavior or a cognition. Many of the definitions include reference to a positive outcome, such as "relief, reward", or "avoid distress."

Cohen and Lazarus (1979:232) have synthesized the work of other researchers (c.f., Moos and Tsu, 1977; Visotsky et al., 1961; Hamburg and Adams, 1967) and have identified the adaptive tasks of physically ill people as:

- 1) to reduce harmful environmental conditions and enhance prospects of recovery;
- 2) to tolerate or adjust to negative events and realities;
- 3) to maintain a positive self-image;
- 4) to maintain emotional equilibrium;
- 5) to continue satisfying relationships with others.

These adaptive tasks imply that coping must be directed toward multiple physical, psychological and social needs, and that it must be directed toward short and long term concerns. This list of tasks also provides a

framework for considering coping in the general context of physical illness and disability.

In this chapter, literature on coping with illness, and the relationship between coping and psychological well-being will be reviewed, and various approaches to the measurement of coping will be discussed.

4.2. Coping as a Personality Trait

Coping has frequently been conceptualized in terms of personality traits. Personality traits or dispositions are seen as leading to consistent patterns of coping response across a variety of situations.

Research has been done on denial as a means of coping among hemodialysis patients (Short and Wilson, 1969) and women waiting for breast cancer biopsies (Katz et al., 1970). Intellectual abilities as coping mechanisms (Fogel and Rosillo, 1973) and dependency and aggression as coping behavior among persons with spinal cord injuries have also been examined (Siller, 1969).

The trait approach to coping has come under sharp criticism. It has been argued that this approach generates information about the relationship between the trait and some type of physiological and/or psychological stress response but not about the actual coping process the person engages in. The coping processes are inferred or assumed on the basis of the definitions of the traits and of obtained relationships with outcome variables (Cohen and

Lazarus, 1979; Folkman, 1979; Folkman and Lazarus, 1980; Lazarus and Launier, 1978; Lipowski, 1970).

The trait approach has also been criticized for its assumptions regarding consistency in coping behavior (Cohen and Lazarus, 1979; Folkman, 1979; Folkman and Lazarus, 1980; Lipowski, 1970). It has been suggested that to the extent that situational demands and the coping options available to deal with the situation influence an individual's choice of coping strategies, trait measures will have limited predictive power.

A third criticism of the trait approach to coping is that it suggests that coping is a unidimensional phenomenon (Cohen and Lazarus, 1979; Folkman, 1980; Lazarus and Launier, 1978). Naturalistic observation indicates that coping is a multidimensional process, with the individual employing an array of coping strategies to deal with any one situation (c.f., Mechanic, 1962; Moos and Tsu, 1977; Murphy, 1974; Visotsky et al., 1961).

Cohen and Lazarus (1973) examined the relationship between trait measures of coping and the actual coping processes and their relationship to an adaptive outcome, recovery from surgery. The process measure of coping was significantly related to only one of the two trait measures, and the process measure was a somewhat more powerful predictor of outcome than either of the trait measures. The authors conclude that a focus on the process of coping will enhance present understanding of coping and its influence on health outcomes.

4.3. Coping as a Process

The study of coping as a process involves the examination of the behaviors and cognitions a person actually employs to cope with a given situation. This approach allows for consideration of the wide array of coping strategies that can be used over the course of coping with a particular situation. Within the conceptualization of coping as a process, coping strategies have been assessed in a variety of ways.

The process approach has been used in studying coping with disabilities such as burns (Andreasson and Norris, 1972; Andreasson et al., 1972; Hamburg et al., 1953) polio (Visotsky et al., 1961) and cancer (Weisman and Worden, 1976).

Several studies (Andreasson and Norris, 1972; Andreasson et al., 1972; Hamburg et al., 1953; Ray et al., 1982; Vistosky et al., 1961) examined coping through the use of repeated, in-depth interviews with a small number of disabled subjects. This method allows for observation of the complexity and sequencing of coping processes. However studies of this type are not readily comparable, as the definition of a given coping strategy will vary from one study to another. While these studies are rich in descriptive data, they permit only general classification of coping modes and a more systematic examination of the coping process is needed to further understand how coping influences health outcomes.

Weisman and Worden (1976) assessed the influence of coping strategies on the psychological well-being of newly diagnosed cancer patients. While this study also involved a series of in-depth interviews, coping responses were coded so as to permit a more systematic analysis. Patients were asked about problems they were experiencing because of the cancer, and what they were doing about them. Open-ended responses were coded into fifteen different coping strategies such as "take firm action based on present understanding," "talking with others to relieve distress," "accept the situation but find something favorable about it" and "laugh it off."

Effectiveness of coping strategies was evaluated by respondents' reports of problem resolution. Problem resolution was rated on a four-point scale ranging from "no resolution at all" to "specific, conclusive, definite resolution." Over the series of interviews, different problems, coping strategies, and resolutions were reported, and the average resolution score was used as a measure of overall coping effectiveness.

Persons who had high levels of problem resolution and were low in emotional distress were termed good copers. Poor copers experienced little problem resolution and greater emotional distress. Good copers tended to take firm action based on their present understanding, accept the situation but find something favorable about it, and comply with their doctor's recommendations. In contrast

poor copers were more likely to try to forget it, fatalistically accept the inevitable, inappropriately act out, and reduce tension by drinking and overeating.

Weisman and Worden's work clearly demonstrates that the way a person copes with the problems that arise from his illness does influence his psychological well-being. However, it can be suggested that Weisman and Worden's use of problem resolution as an indicator of coping effectiveness is not entirely adequate. All problems that were completely resolved were seen as indicative of effective coping regardless of whether the respondent viewed the outcome as satisfactory or not. One might reasonably assume that at least some of the time a definitive, yet unfavorable resolution of a problem is indicative of ineffective coping. Further, the use of an averaged measure of coping effectiveness fails to take into account that certain coping strategies might be effective for certain types of problems and not others, and persons might effectively deal with certain types of problems and not others.

Recently several researchers have developed standardized instruments for assessing coping strategies. A distinct advantage of this approach is that it permits greater comparability across populations and types of problems. Folkman (1979: 120) has stated that "although strategies such as 'took one step at a time', 'sought sympathy or understanding', and 'tried not to think about the problem' might differ in the ways they are carried out

in various settings, the core of the strategy as captured in the item is applicable in any setting."

An 18-item coping checklist was used by Bell (1977) in a comparison of the coping strategies of thirty psychiatric in-patients and a group of normal controls. Items were categorized as either long-term or short-term coping methods. Long-term methods comprise "constructive, realistic ways of coping with stress that can effectively relieve stress for long periods of time" (1977:137). Included among long-term coping strategies are talking it over with others, finding out more about the situation, physical exercise as tension release, and definite action. Short-term coping methods are those that "may reduce stress and tension to a tolerable limit temporarily, but which, carried on for long periods of time do not deal with reality and may have a destructive or detrimental effect on the person" (1977:137). Short-term methods include the use of alcohol and drugs, crying and involvement in other activities to keep from worrying. Respondents were asked to indicate how often they used each strategy to deal with stress. A five point response scale, ranging from "never likely to use this strategy" to "always likely to use this strategy" was employed.

It was found that the psychiatric in-patients used significantly more short-term coping methods than did the controls. However in both groups persons who were experiencing elevated levels of life stress were more

likely to use short-term coping methods for dealing with stress. Bell interprets these findings as indicating that inadequate coping in adapting to life changes might increase the probability of disease occurrence.

While Bell did find some significant differences between groups in the use of short and long-term coping strategies, the validity of this dichotomy of strategies is questionable. It can be argued that such a dichotomy should be derived empirically rather than according to an investigator's a priori theory. Beyond this, it can be suggested that Bell's intuitive division lacks even face validity. The differentiation between short and long-term methods seems to be based on her view of what is effective, constructive coping versus what she sees as ineffective, destructive coping. For example, it is not clear that "I work it off by physical exercise" (long-term) is substantially different from, or more effective than "I become involved in other activities to take my mind off the problem" (short-term). In fact, those other activities might include physical exercise.

Another limitation of Bell's study is that persons completed the coping checklist in terms of how they dealt with stress and tension in general. However, it is possible that people use different coping strategies in response to various stressors. Research that focuses on how people cope with specific stressful situations may further understanding of the relationship between coping

strategies and psychological health.

Other studies, while not specific to illness situations, have examined the influence of coping strategies on psychological health, and have presented interesting measures for the assessment of coping strategies.

Berman and Turk (1981) examined the influence of coping strategies on psychological distress following divorce. Subjects were presented with a 45-item checklist designed to assess the nature of problems experienced during the process of adapting to divorce. Each item was rated on a 4-point scale according to the frequency with which the item was perceived to be a problem or worry. Coping strategies were evaluated through a 53-item checklist that included items such as 'dating', 'reading', 'buying all kinds of things' and 'never showing fear'. The perceived efficacy of each coping strategy was rated on a 4-point scale ranging from "not at all helpful, or never used" to "very helpful."

Factor analyses indicated six problem factors and six coping strategy factors. The coping strategy factors were: 1) social activities; 2) learning; 3) personal understanding; 4) expressing feelings; 5) autonomy; 6) home and family activities.

Regression analysis indicated that two coping factors, social activities and autonomy, were significantly related to a positive mood state, and expressing feelings was significantly related to a negative mood state. The

other three coping factors were not significantly related to mood state. Life satisfaction was significantly and positively related to three coping factors - social activities, home and family activities, and autonomy. Expressing emotions was negatively related to life satisfaction, and there was no significant relationship between life satisfaction and personal understanding and learning.

The relationship between coping factors and problem factors was examined through correlational analysis. Two coping factors, social activities and autonomy, were significantly and negatively correlated with loneliness and interpersonal problems. None of the other problem factors was significantly related to the other coping factors. The authors interpret this as indicating that some coping strategies are problem-specific, rather than globally applicable.

However it can be argued that the researchers failed to obtain significant correlations between most problem factors and coping factors, in part, because of their methods. While respondents indicated the frequency with which they experienced specified problems, they indicated only how they coped with problems in general, rather than how they coped with specific problems. It is possible that respondents employ different coping strategies for different problems, and the methods used in this study do not allow for this observation. Thus it is not surprising

that significant correlations between problem factors and coping factors were not obtained in most instances.

In the intriguing study of Pearlin and Schooler (1978) the focus was on the ways "normal" people coped with the strains of everyday living. Subjects were 2,300 people between the ages of 18 and 65 years who were representative of a large urban population. The interview schedule was designed to collect information on strains in four role areas and to assess the coping repertoires people employ in dealing with the strains they experience in these roles. The role areas studied were: 1) marriage; 2) parenting; 3) worker; 4) household financial manager.

Pearlin and Schooler (1978) used a three level system for classifying coping. At the highest level are three major types of coping that are distinguished from one another by the nature of their functions. These are: 1) responses that change the situation out of which strainful experience arises; 2) responses that control the meaning of the strainful experience after it occurs but before the emergence of stress; 3) responses that function more for the control of stress itself after it has emerged.

The second level comprises 17 empirically derived factors, such as self-reliance vs. advice-seeking, negotiation, and selective ignoring. These factors represent types of coping as compared to the strategies that make them up. Strategies constitute the third and most specific level. For example the factor "controlled

reflectiveness vs. emotional discharge" in marriage comprises "yelling to let off steam", "thinking over marital problems", and "reading books or magazines about how to get along in marriage". Each of these factors represents at least three coping strategies.

Certain coping response factors such as selective ignoring and positive comparisons were used to deal with strains in all four role areas while other coping factors were context specific. For example, "negotiation" was used only in marriage and "exercise of potency vs. helpless resignation" appeared only in household economics. This suggests that certain strategies have fairly universal application and others are applicable only in certain contexts.

Pearlin and Schooler (1978) evaluated the effectiveness of the coping factors in terms of their ability to alleviate psychological distress. Regression analyses were conducted to examine the effect of coping factors in reducing psychological distress within each role, taking into account the degree of role strain. Results indicated that whether or not the strains people experienced in their marriage led to emotional distress depended to a substantial extent on their coping responses to the strains. Coping exerted less influence on the relationship between strain and emotional distress in parental and economic roles, and made no difference to this relationship in the occupational role. It was found that

the use of certain coping response factors served to reduce emotional distress in some role areas and increase distress in others. Analyses indicated that, except in occupation, more effective and less effective coping responses could be discerned. At the same time the effect of any single coping factor was modest.

Folkman (1979) has approached coping through the cognitive phenomenological theory of stress developed by Lazarus and his colleagues (c.f., Lazarus, 1966; Lazarus and Launier, 1978; Lazarus et al., 1974). Within this theory, coping is seen as one of the major processes that mediates the person-environment relationship. It serves two main functions: the alteration of the person-environment relationship (problem-focused coping) and the regulation of stressful emotions (emotion-focused coping). Problem-focused coping refers to cognitive and behavioral efforts to deal with the source of stress either by changing one's own behavior, the environmental condition or both. Emotion-focused coping refers to cognitive and behavioral coping efforts aimed at reducing emotional distress to maintain a satisfactory internal state for information processing and action.

These two dimensions of coping responses appear to be conceptually similar to the three major types of coping responses proposed by Pearlin and Schooler (1978). Problem focused coping strategies can be seen as similar to strategies that Pearlin and Schooler have identified as

functioning to change the situation out of which strain arises. Emotion focused coping strategies appear to be in the same conceptual domain as those strategies identified by Pearlin and Schooler as functioning to either control the meaning of the strainful situation before the emergence of stress or to control stress itself after it has emerged.

Based on this conceptual framework Folkman (1980) developed the Ways of Coping checklist. This is a 68-item scale describing a broad range of behavioral and cognitive coping strategies that an individual might use in a specific stressful episode. Factor analyses showed 27 items were problem-focused, and 41 items were emotion-focused.

The checklist was used to assess how 100 persons from a general population coped with stressful events. Subjects were interviewed seven times at 4 week intervals and each time were asked to report a stressful event that occurred during the previous month, and what they did or were doing about it. Results indicated that in virtually every stressful encounter, both problem-focused and emotion-focused coping strategies were used. The context of the stressful event, that is, whether it was work-related, family-related or health-related, was found to differentially influence the use of problem and emotion-focused coping. Work was associated with higher levels of problem-focused coping, and health was associated with increased emotion-focused coping. The increase in emotion-focused

coping associated with health problems is consonant with other studies (Moos, 1974; Lipowski, 1970) that have found that much of coping with illness and disability is directed towards managing feelings of anxiety and fear and maintenance of self-esteem. Family problems did not have a clear impact on either problem or emotion-focused coping, and the author suggests this may be due to the heterogeneity of episodes grouped within this category.

This study has clearly demonstrated that a single coping checklist can be successfully utilized for the assessment of coping responses in a wide array of situations and that the different functions of various coping strategies can be observed. While the Ways of Coping Scale appears to be comprehensive, its length could be a drawback in survey research where there is a need for inclusion of a wide array of variables. There is a clear need for a measure that can more easily be incorporated in survey research.

4.4. The Relationship Between Social Support and Coping

Both social support and coping have been shown to independently influence psychological well-being. It may also be that these phenomena are importantly related to each other and have significant combined effects on psychological well-being. However there is little research on the relationship between coping and social support.

Pearlin et al. (1981) included both social support

and coping as mediators in their study of how stressful life events influence the onset of depression. They state that:

...although they are two distinct phenomena, they have similar functions in the stress process. While the mobilization and use of social resources are different from the mobilization and use of coping strategies, each has the capacity to regulate effects of stressful conditions. The individual, faced with an array of problems and hardships as he moves through the life course, does not choose between coping or supports, but uses both in an effort to avoid, eliminate or reduce distress (1981:13).

However while Pearlin et al. (1981) suggest that social support and coping serve similar functions, they treat coping and social support separately in their analyses, and the relationship between these variables is not discussed.

Similarly Andrews et al. (1978) examined the effects of social support and coping on psychological distress. Both these variables were found to be independently associated with psychological distress but, as in the study of Pearlin et al. (1981) the relationship between coping and social support was not assessed.

A few investigators have recently proposed that there may be an important relationship between social support and coping, and the interaction of these variables may have a significant impact on psychological health status. DiMatteo and Hays (1981) suggest that an individual's coping style may mediate the effects of social support and that future progress in understanding how social support

influences health outcomes among ill persons will be enhanced by an increased knowledge of coping styles. Turk (1979:101) discusses the adaptive process among the chronically ill and states that the quality of the adaptive process will be influenced by knowledge of "appropriate coping strategies and social supports available to help patients deal with both the emotional arousal generated during the course of the illness and the specific illness-related problems that are encountered."

Hirsch (1981:165) has suggested that future research be directed to the study of "the role of social network in the coping process." In a study of social support, social networks, coping and several dimensions of psychological well-being, Hirsch (1980) suggested that social networks can facilitate adaptive coping. Among a group of women experiencing major life changes, low density, multi-dimensional social networks were associated with greater psychological well-being and greater satisfaction with social roles than were high density, unidimensional networks. Based on this Hirsch suggested that certain types of social networks can help to achieve the coping objective of developing rewarding social roles appropriate to current life circumstances.

However Hirsch's (1979, 1980, 1981a, 1981b) use of the term coping appears to be problematic when considered in light of much of the current literature on the coping process. To suggest, as Hirsch appears to do, that because

social support is associated with good psychological health. Social support allows one to cope adequately, is to obscure the differences between social support and coping. While much of the recent research indicates that the use of social supports may be an important coping strategy, it is only one of many possible coping strategies. Social support and coping must be considered as distinct but related dimensions if further progress is to be made in the study of these constructs.

There are several ways in which social support and coping strategies could influence each other. Social support might influence one's choice of coping strategies, and the coping options that are available. For example persons without confidants may be unable to use the coping strategy "talked to other people about the problem." Availability of support, and discussion of problems with supportive network members may introduce the individual to coping options he was unaware of, or may encourage the individual to employ strategies he was hesitant about, or felt were too risky.

Alternately, the use of certain coping strategies may influence the level of social support that is available to an individual. A person who copes by "yelling and shouting to let off steam" or "takes it out on other people" may reduce the level of support that is available to him. It may be that coping strategies that involve self-pity, self-deprecation and the expression of anger and hostility

toward others alienates network members and inhibits support.

Under certain circumstances an individual might increase support through the use of coping strategies such as "went on as if nothing had happened", "tried to look on the bright side of things", and "made a plan of action and followed it." Coping strategies that indicate a sense of responsibility for working towards resolution of the problem, and a desire for understanding and empathy from others may enhance the level of support available to an individual.

This study will assess the relationship between social support and coping strategies, and will provide an opportunity for examination of their combined effects on psychological adjustment. Such an analysis will not only provide needed information on the relationship between these two phenomena but will further present understanding of the independent as well as combined effects of these variables on psychological adjustment.

4.5. Summary

There have been a variety of approaches to the study of coping with illness, and of the influence of coping on psychological distress. These studies indicate that how one copes does make a difference to illness outcome and psychological health.

There is a great need for further research on how

people cope with long-term disability and its attendant problems. Much of the coping research has been plagued by methodological weaknesses. There has been little research on how the disabled living in the community cope with the problems of disability and at present the kinds of coping strategies that are used, and the effectiveness of different coping strategies for dealing with the problems of physical disability are not well understood. An increased understanding of the coping process is likely to have significant implications for rehabilitation counselling and for lessening the extent of psychological distress among the disabled.

CHAPTER 5

METHODS

5.1. Research Questions.

While elevated levels of psychological distress have been found among the disabled, the factors that influence psychological health status within this population are not well understood. Two factors, social support and coping strategies, have been shown to importantly influence psychological health status but these variables have not been well researched within a disabled population. This study examines their influence on psychological adjustment among a group of disabled persons and specifically addresses the following questions:

- 1) What is the relationship between social support and psychological adjustment among persons with physical disabilities?

What is the role of life events stress in the social support/psychological distress relationship?

- 2) What is the relationship between coping strategies and psychological adjustment among the disabled? Is there a relationship between type of problem, coping strategies, and psychological adjustment?

Does the relationship between coping and psychological adjustment vary depending on the stressfulness of the problem? What is the relationship between social support and coping strategies?

5.2. Sampling Procedures

5.2.1. Sampling Frame. The sampling frame was composed of adults aged 18 and over with long-term or permanent physical disabilities living within a ten county area of Southwestern Ontario. The catchment area included Middlesex, Oxford, Elgin, Perth, Huron, Bruce, Grey, Essex, Lambton and Kent counties.

The data presented in this study are part of a larger investigation into the rehabilitation potential of the physically disabled in Southwestern Ontario, and the catchment area was determined by the needs of the larger study.

Persons whose physical disabilities had a duration of three months or more were included in the sampling frame. In cases where the condition was of shorter duration, questions were asked about the anticipated duration. If the respondent anticipated a duration of more than three months, he was included in the sampling frame.

Physically disabled adults who also had mental handicaps, and those who were living in institutions for the disabled or aged were excluded from the sampling

frame. Also excluded were those with an insufficient knowledge of English to complete the interview, those with severe speech problems caused by conditions such as cerebrovascular accidents, and persons who, while considered non-institutionalized, were absent from their homes because of long-term and/or indefinite hospitalization.

5.2.2. Sampling Procedures. A multi-stage clustering technique was used to obtain the sample. The primary sampling units were enumeration areas (EAs) as defined in the 1976 Canadian Census (Statistics Canada, 1976). Enumeration areas are designated by Statistics Canada (1976) as urban or rural on the basis of total population and population density. In recognition of the possible influence of rural-urban differences on study variables, the EAs were stratified on this factor. As it has been estimated that disability is more prevalent in urban than rural areas (Peat, Marwick et al., 1975), rural EAs were over sampled. Therefore the EAs were allocated proportional to the square root of the population count, resulting in a 60/40 allocation to urban/rural areas. Thus the basic sample of primary sampling units was composed of 120 urban EAs and 80 rural EAs.

Twenty replacement EAs were sampled in the same proportion, yielding twelve urban replacement EAs and eight rural replacement EAs. Six of the rural replacement EAs were substituted for six of the original rural EAs because the high proportion of non-permanent country residences in

these original EAs could have decreased the reliability of sampling.

The second stage of sampling involved the selection of households within the EAs. To obtain the desired proportion of rural disabled in the resulting sample of individuals, a larger sampling fraction was used in rural areas than in urban areas. In urban areas one in every five households was screened and in rural areas one in every 2.5 households was screened. Data from the 1976 Canadian Census (Statistics Canada, 1976) were used to estimate the number of households to be screened in each area. Interviewers were given a map of each EA, marked with a starting point, and asked to select every fifth or 2.5th household in the enumeration area.

Only private residences were eligible for inclusion in the sample of households. Institutions for the physically disabled or the aged were not included in the sampling frame, and were not screened. Within each household, all persons age 18 and over were eligible for inclusion in the screening phase.

5.2.3. Sample Size. The sample size for this study was based on the number of cases needed to adequately address the two major research questions. Sample size requirements for each of these questions are discussed below:

- 1) What is the relationship between social support and psychological adjustment among the physically disabled?

It was anticipated that this question would be approached through correlational analysis. Earlier research has indicated a correlation of approximately .30 between social support and psychological distress (c.f., Turner, 1981). The magnitude of the minimum correlation of interest between social support and psychological distress is one factor that determines the required number of observations. The desired significance criterion, and the desired power of the statistical test also influence the required sample size. To determine the sample size required to satisfactorily address this research question, the significance level, for a two-tailed test, was set at .01, a power of .80 was specified, and the size of the true correlation between social support and psychological distress was estimated at .30. With these specifications, tables presented by Cohen (1977:102) indicated that 124 cases were needed.

2) What is the relationship between coping behaviors and psychological adjustment?

Sample size requirements for this question were also based on correlational analysis. Previous research on the relationship between coping and psychological distress has produced zero-order correlations of approximately .30 (c.f., Berman and Turk, 1981). When the significance level, for a two-tailed test was set at .01, a power of .80 was specified, and the population correlation was estimated at .30, a sample of 124 cases was required to

address this question (Cohen, 1977:102).

Amendments were made to these sample size requirements in order to compensate for the increased sampling error that derives from the use of cluster sampling. This involved compensation for the design effect factor (DEFF), which is the ratio of the variance of cluster sampling to the variance of a random sample of the same size. Estimation of the DEFF for this study was based on work by Kish and Frankel (1970). In an American National Centre for Health Statistics Survey they found a DEFF of 1.64 for simple correlations and 1.82 for partial correlations. The more conservative measure $DEFF = 1.82$, was used as the estimated DEFF in this study. As both research questions required the same number of cases, the required sample size was then:

$$124 \times 1.82 = 225.68$$

Thus all research questions can be adequately addressed with a sample of 225.68 respondents. As the larger study, from which these data are drawn required a sample of approximately 1,000, the final sample consists of 989 cases. Thus the sample size is more than sufficient to conduct all analyses.

5.3. Data Collection Procedures

5.3.1. Interviewers. Thirty interviewers, spread over the ten counties, gathered data for the study.

Interviewers were selected on the basis of prior experience and a practical demonstration of interviewing skills.

Group training sessions were held and each interviewer's work was assessed periodically throughout the data collection phase. Interviewers were randomly assigned enumeration areas, within their counties. All interviewers signed an oath of confidentiality upon being hired.

5.3.2. Screening Phase. Each enumeration area was screened by a single interviewer. At each selected household, data were collected on the age and sex of persons over 18 years of age and on whether there was anyone with a disability in the household.

The following question was used to determine eligibility for participation in the study:

Do any adults in the household have any physical health condition or physical handicap that has resulted in a change in their daily routine or that limits the kind or amount of activity they can carry out? (For instance: work, housework, school, play-recreation, shopping or participation in social activities or community activities.)

This question was asked of the person who answered the door, and not specifically of each individual in the household or of the disabled individual. If the response to this question was affirmative, questions on the type and duration of health problems were asked. The screening interview thus both identified the disabled and determined whether the disabled individual met the criteria for inclusion in the sampling frame.

5.3.3. The In-Depth Interview of the Disabled. At each house where a disabled person was identified, an in-depth interview was requested. The request for an interview was made either directly to the disabled individual or to a proxy. If the proxy was unwilling to arrange for an interview with the disabled individual, the interviewer telephoned or called back in person to discuss arrangements for an interview.

All potential subjects were provided with an explanatory letter that described the study, the voluntary nature of participation and the confidentiality of the interview. This letter is shown in Appendix B.

If consent for an interview was given the interview took place immediately following the screening interview, or at a later, more convenient time. The interview of the disabled was conducted by the same interviewer who had made the initial screening contact. The interview lasted approximately one and a half hours. Questions pertained to the physical disability, psychological health status, social support, coping behaviors, demographic variables, and medical care variables.

Confidentiality of respondents was maintained by assigning an identification number to each respondent. As completed questionnaires were returned to the office, the cover sheet containing all identifying information was removed and placed in a locked filing cabinet. The master list of names and numbers was also kept locked. Access to

these files was restricted to members of the project staff, all of whom had signed an oath of confidentiality at the beginning of their employment.

5.4. Participation Rates and Analyses of Lost Cases

5.4.1. Participation Rates. A total of 11,959 households were contacted for the screening interview, and the interview was completed at 10,972 households. From the completed screenings 22,680 adults aged 18 and over were identified, among whom 1509 had physical disabilities. Seventy three of the disabled persons identified were excluded from participation in the in-depth interview because they did not meet all the selection criteria. Nine hundred ninety-five disabled persons participated in the in-depth interview. This represents a response rate of 69.29 percent. Six of these interviews could not be used in data analysis because of excessive missing data. Thus the final sample for data analysis in this study consists of 989 cases.

Data on participation rates for the screening and in-depth interviews are presented in Tables 5.1 and 5.2.

Efforts were made to reduce the non-response rate as much as possible. Up to four calls were made at each household to reduce non-response to the screening interview due to not-at-homes.

The refusal rate (31%) for the in-depth interview of the disabled is considerably higher than for the

Table 5.1

PARTICIPATION RATES FOR THE SCREENING INTERVIEW

	N	%
Total Households Contacted	11,959	100.00
Screening Completed	10,972	92.00
Screening Refused	248	2.00
Not-at-Homes	739	6.00

Table 5.2

PARTICIPATION RATES FOR THE IN-DEPTH
INTERVIEW OF THE DISABLED

	N	%
Total Identified	1,509	
Exclusions (language difficulty, long term hospitalization)	73	
Eligible Total	1,436	100.00
Participated	995	69.00
Refused	441	31.00

screening interview (2%). This is to be expected, given the length and nature of the interview, as well as the fact that respondents were often in poor health.

In an effort to reduce the refusal rate of the in-depth interview, a second explanatory letter concerning the study and encouraging the respondent to reconsider his participation was sent to 66 persons in the London area who had initially refused the in-depth interview. Approximately one week after the letter was sent interviewers contacted these individuals by telephone to discuss the interview. Only nine interviews were obtained through this procedure. Given this low response rate, it was decided that a more widespread letter campaign would not significantly increase the response rate, and no further letters were sent. Appendix B presents a copy of the letter sent to the refusers.

5.4.2. Analyses of Lost Cases. Cases that were lost to the study, either by exclusion or refusal, were compared with completed cases in terms of age, sex, urban or rural residence, type of physical disability and duration of condition.

Data on the age distribution of completed and lost cases is presented in Table 5.3. The age of participants is significantly different from that of the lost cases ($t=6.35$, $p<.001$). The mean age of participants is 55.98 years, compared with a mean of 61.50 years for the lost cases. The significant difference in age between the

Table 5.3

COMPARISON OF COMPLETED AND LOST CASES BY AGE

AGE GROUP	COMPLETED CASES		LOST CASES	
	<u>N</u>	<u>%</u>	<u>N</u>	<u>%</u>
18-49	318	32.0	100	19.7
50-64	337	33.9	163	32.0
65-74	222	22.3	146	28.7
<u>75+</u>	<u>118</u>	<u>11.8</u>	<u>100</u>	<u>19.6</u>
Total	995	100.0	509	100.0
Mean Age	55.98 years		61.50 years	

$t = 6.35, p \leq .001$

participants and the lost cases appears to be due primarily to the high percentage of lost cases among persons 65 years and older. While more than 47 percent of the lost cases were 65 years or more, less than 34 percent of the participants were that old. This suggests that the study findings may be less generalizable to persons over age sixty-four.

Analysis of the completed and lost cases by residence - rural or urban - also showed significant differences between the two groups ($X^2 = 6.11$, $P < .05$), with the lost cases having a slightly greater percentage of urban residents (67.5%) than the completed cases (61.2%). While these differences are statistically significant, they are in practical terms, not large and it is not expected that they will have a significant impact on the research questions to be addressed here.

Other analyses indicated no significant differences between the completed and lost cases in terms of sex, type of physical disability or duration of the physical disability. Results of analyses on these variables are presented in Appendix D.

5.5. Data Processing

All data collected during the study were coded according to a standardized coding scheme. A reliability check was conducted on every fifth interview. The error rate was less than one per cent and non-systematic.

In those cases where coding required judgemental decisions, coding was done independently by two individuals and any discrepancies in coding were resolved through discussion. Thus all codes of health conditions, occupations, and coping problems were agreed on by two people. Two registered nurses coded the health conditions.

The data were also subjected to standard computer cleaning practices. As a consequence of these procedures, the analyses presented here are based on highly accurate data.

5.6. Instrument Development

A screening instrument was developed and pre-tested in a small door-to-door survey. Based on the pretest, some changes to the instrument were made. The final version of this instrument is shown in Appendix A.

The questionnaire for the disabled was pre-tested on a small sample of persons with diverse disabilities who were obtained through a rehabilitation medicine specialist's practice. These individuals were not included in the final sample. Some modifications to the questionnaire were made after examination of the pre-test results. The final version of the questionnaire is presented in Appendix A.

5.7. Measurement

In this section, the following measures will be discussed:

- 1) disabling conditions
- 2) psychological adjustment
- 3) social support
- 4) coping
- 5) functional status
- 6) stressful life events

Several of the instruments are widely used and information is available on reliability and validity. Other measures have not been used in previous research. Information on the formal properties of each measure, based on the study data, will be presented. The reliabilities of these measures were assessed through the use of Cronbach's coefficient alpha (Cronbach, 1951) for inter-item consistency.

5.8. Disabling Conditions

Physical disability is defined in this study in terms of a limitation in the kind or amount of activity a person can perform that results from a chronic health condition or impairment lasting three months or longer or that is anticipated to be of long-term or permanent duration.

Respondents who had been identified in the screening interview as limited in activities because of a health problem were asked "What physical problem would you say is the main cause of your limitation?" Other questions asked about secondary disabling conditions. Responses to these questions form the basis for the impairment categories used in this study.

All disabling conditions were initially coded

Table 5.4

FREQUENCIES OF TEN DISABILITY CATEGORIES

DISABILITY	N	%
neoplasms	26	2.6
endocrine, metabolic, blood forming and genitourinary disorders	36	3.6
nervous system	79	8.0
circulatory system	231	23.4
respiratory system	78	7.9
digestive system	20	2.0
skin and musculoskeletal disorders	380	38.4
fractures and trauma	53	5.4
deformities (amputations, vision and hearing impairments, spine and limb deformities)	83	8.4
unspecified and ill- defined disorders	3	.3
TOTAL	989	100.0

according to a modified version of the International Classification of Health Problems in Primary Care (1979). This coding scheme allowed for individual coding of each impairment and for classification of each impairment in larger disease, injury and/or body system categories. Impairments were then recoded into the 10 categories shown in Table 5.4.

The nervous system category is composed of brain and spinal cord disabilities such as multiple sclerosis, cerebral palsy, epilepsy and Parkinsonism. The major conditions coded under circulatory system are heart disease, hypertension and cerebrovascular conditions. Conditions coded within the skin and musculoskeletal category include all types of arthritis, vertebral column syndromes and connective tissue disorders. These 10 categories were selected for their inherent logic, based on disease and injury classifications and body systems, and for their comparability with the classification schemes of several major disability surveys (Allan, 1976; DHEW, 1981). Table 5.4 indicates that skin and musculoskeletal disorders were the most frequently named major disabling conditions, occurring in approximately 38 percent of the disabled. Circulatory problems were the major disabling condition for 23.4 percent of the sample. Considerably lower frequencies were reported in each of the other impairment categories.

5.9. Measures of Psychological Adjustment

5.9.1. Measures of Anxiety, Anger/Aggression and Self-Esteem. In assessing psychological adjustment among the disabled, the dimensions of anxiety, anger/aggression and self-esteem were thought to be particularly relevant. Anxiety is widely recognized as an indicator of psychological distress and previous research has indicated that elevated levels of anxiety and low levels of self-esteem are common among the disabled. Feelings of anger/aggression are likely to be important among a group of disabled individuals.

The scales for assessing these three dimensions were taken from a larger instrument designed to assess psychological well-being called the "How I Feel" (Petersen and Kellam, 1977). Twenty items were selected for use in this study. For each item the respondent is asked to rate himself on a five-point scale ranging from "not at all like me" to "very much like me." In this study higher scores indicate higher levels of anxiety and anger/aggression and lower self-esteem.

There is evidence for the satisfactory reliability of the "How I Feel" and each of its subscales (Petersen and Kellam, 1977).

Several of the relevant subscales have been used in studies at the Health Care Research Unit at The University of Western Ontario. The samples for these studies have included mothers of newborn infants, adults with impaired

Table 5.5

COMPONENT ITEMS AND STANDARDIZED ITEM ALPHAS
FROM SEVERAL SAMPLES ON "HOW I FEEL" SUBSCALES

CONSTRUCT	ITEMS	NEW MOTHERS (N = 236)	MALADAPTIVE PARENTS (N = 465)	UNIVERSITY STUDENTS (N = 190)	HEARING IMPAIRED ADULTS (N = 421)	PHYSICAL DISABILITY (N = 989)
Anxiety (7 items)	I feel nervous. I feel under pressure. My hands sometimes shake. I feel tense. New situations make me tense I feel tight inside. I startle easily.	.74	.72	.73	.83	.82
Self Esteem (7 items)	I feel strong and healthy. I can change my plans or mind if I get new information. I like being the way I am. I'm good at what I do. When faced with a problem, I can work it out.	.72	.64	.75	.77	.62
Anger/ Aggression (6 items)	When I get angry, I stay angry. I yell at people. I feel like I am boiling inside. I lose my temper. I feel angry. I get into fights or arguments.	.76	.74	.83	.74	.78

asked to rate how closely each statement describes their relationship by answering on a five-point scale ranging from "very much like my experience" to "not at all like my experience". Higher scores indicate greater support.

The PSR was pretested on a convenience sample of 200 university students. It was thought that a scale that appeared to be a satisfactory measure of support among a student sample would also be satisfactory with other populations. While the pretest analysis showed satisfactory alpha coefficients for four of the five dimensions of support, these results were not replicated in this study. Only two of the dimensions had satisfactory alpha coefficients.

Factor analysis, calling for a varimax rotation with an orthogonal solution produced three factors with eigenvalues greater than one. However these factors did not resemble the dimensions of support as initially conceived. Instead, most items appeared to factor in terms of sources of support.

To further evaluate this, factor analysis was done with two orthogonal factors specified. All but three of the 18 items clearly factored into one of the two dimensions. These three items were dropped from the scale. Factor analysis on the 15-item scale confirmed the two factors. These factor analyses are shown in Table 5.8. The first factor contains six items assessing the dimensions of family support while the second is composed of

hearing, and ex-psychiatric patients. In addition 200 university students completed the anxiety, anger/aggression and self-esteem subscales. The component items and the alpha coefficients for each of these groups, and for the study sample, are presented in Table 5.5. Alphas of .60 or higher are considered to be acceptable evidence for reliability (Cronbach, 1951). Thus each of the subscales appears to be internally consistent.

There is some evidence for the validity of these scales. Petersen and Kellam (1977) report that the scales do discriminate between normal and clinical populations, and they correlate with other measures of psychological distress.

5.9.2. Centre for Epidemiological Studies Depression Scale. Depression is one of the most widely recognized indicators of psychological distress, and elevated rates of depression among the disabled have frequently been reported. In this study depression is measured by the Centre for Epidemiological Studies Depression Scale (CES-D). The CES-D is a twenty-item scale designed to measure an individual's current level of depressive symptomatology, with emphasis on depressed mood. On a four-point scale ranging from "rarely or none of the time" to "most or all of the time" respondents are asked to indicate how often they experienced each of the symptoms in the last week. Higher scores indicate greater depression.

The CES-D appears to be highly reliable. In four

separate field tests of the scale Cronbach's (1951) alpha ranged from .84 to .90, (Radloff, 1977). In the study sample coefficient alpha for the CES-D is .90.

Evidence for the validity of the CES-D is also available. The scale has been found to discriminate well between psychiatric in-patient and general population samples and to discriminate moderately well among levels of severity within patient groups (Radloff, 1977). The CES-D also correlates well with other self-report measures of depression (Radloff, 1977).

5.9.3. Use of These Measures in Analyses. Various combinations of the anxiety, anger/aggression, self-esteem and depression measures are used in analyses. These measures form the basis for assessing two dimensions of psychological distress - depression, measured by the CES-D Scale, and general distress. An index of general distress was created by standardizing scores on the anxiety, anger/aggression and CES-D Scales, in order to achieve equal weighting, and then summing the scores.

The 7-item self-esteem scale is employed as a single measure in analyses. Self-esteem has been referred to as an important component of "positive mental health" (Jahoda, 1958). Self-esteem and psychological distress can thus be seen as opposite ends of a mental health continuum. However as self-esteem and psychological distress are distinct dimensions, analyses on these dimensions of adjustment will be presented and discussed separately.

5.10. Social Support

5.10.1. The Revised Kaplan Scale. The Revised Kaplan Scale is a measure grounded in Cobb's (1976) conceptualization of support as comprising information that one is loved, esteemed, and a member of a social network. Anne Kaplan (1977), a student of Cobb's, proposed and partially tested a story-identification technique composed of sixteen sets of vignettes. Seven sets were adopted for use as a measure of support at the Health Care Research Unit. When this seven-item measure was used in four major studies at the Health Care Research Unit, Cronbach's alphas ranged from .78 among a group of healthy new mothers to .83 among a group of hearing impaired adults (Turner, 1981).

As the seven-item scale did not permit reliable identification of the dimensions of love, esteem, and network support the scale was extended and elaborated initially into eleven items. Two items were subsequently dropped, one because it did not factor well and one because of redundancy. The nine-item scale finally adopted includes two entirely new sets of vignettes, five sets where slight modifications were made from the Kaplan originals and two sets in their original form. Table 5.6 presents a sample page of the vignettes. Each set is scored from one to five, with high scores indicating greater support. The nine scores are summed.

To assess the dimensions of this scale, factor analysis employing a varimax rotation with an orthogonal

Table 5.6

SAMPLE VIGNETTES AND STANDARDIZED ITEM ALPHAS
FOR THE REVISED KAPLAN SCALE

DEBBIE

LESLIE

ROBIN

People are devoted to Debbie and love her. They always support her, listen to her and sympathize with her. They care about her a lot.

People are usually fond of Leslie. They can be sympathetic, but do not always listen to her or support her.

People are not devoted to Robin. They do not support her, listen to her or sympathize with her. They do not care about her or love her.

Check the box that best applies to you.

☐☐☐☐☐

I'm like Debbie.

I'm halfway between Debbie and Leslie.

I'm like Leslie.

I'm halfway between Leslie and Robin.

I'm like Robin.

STANDARDIZED ITEM ALPHAS FROM TWO SAMPLES

CONSTRUCT	PHYSICAL DISABILITY	MENTAL* HEALTH
Love-Esteem Support	.79	.87
Network Support	.73	.78
Summary Measure	.83	.81

*Source: Turner et al., in press

Table 5.7

FACTOR ANALYSIS ON THE REVISED KAPLAN SCALE
 USING VARIMAX ROTATION WITH OBLIQUE SOLUTION

DIMENSION	ITEM NO.*	FACTOR 1	FACTOR 2
LOVE	1	.62	-.05
	4	.34	-.25
	7	.77	-.00
ESTEEM	2	.49	-.16
	5	.65	-.11
	8	.39	-.30
NETWORK	3	.04	-.61
	6	.07	-.83
	9	.10	-.59

*Item No. refers to the order in which the items were originally administered.

solution was done. This produced only two factors - one including all love support and esteem support items, and the other including the social network items. Because these two dimensions were found to be highly correlated ($r=.58$) factor analysis was repeated calling for an oblique solution, and the two dimensions were again produced. This factor analysis is shown in Table 5.7. From these results it appears that love support and esteem support have the same underlying determinants and hence represent a single dimension. The Revised Kaplan is thus a two dimensional scale.

Alpha coefficients (Cronbach, 1951) for each of the subscales and a summary measure, based on the study sample and a study of ex-psychiatric patients, are shown in Table 5.6. As would be expected, given the factor based subscales, the alpha coefficients demonstrate satisfactory reliability.

5.10.2. The Provisions of Social Relations Scale.

The Provisions of Social Relations (PSR) Scale was developed by the author and associates at the Health Care Research Unit. The conceptualization of this scale was importantly influenced by Weiss' (1974) discussion of the provisions of social relationships, and items were developed in an effort to assess subjects perceptions in relation to five of the "provisions" identified by Weiss (attachment, social integration, reassurance of worth, reliable alliance, and guidance).

For each of the 18 items in the scale respondents are

asked to rate how closely each statement describes their relationship by answering on a five-point scale ranging from "very much like my experience" to "not at all like my experience". Higher scores indicate greater support.

The PSR was pretested on a convenience sample of 200 university students. It was thought that a scale that appeared to be a satisfactory measure of support among a student sample would also be satisfactory with other populations. While the pretest analysis showed satisfactory alpha coefficients for four of the five dimensions of support, these results were not replicated in this study. Only two of the dimensions had satisfactory alpha coefficients.

Factor analysis, calling for a varimax rotation with an orthogonal solution produced three factors with eigenvalues greater than one. However these factors did not resemble the dimensions of support as initially conceived. Instead, most items appeared to factor in terms of sources of support.

To further evaluate this, factor analysis was done with two orthogonal factors specified. All but three of the 18 items clearly factored into one of the two dimensions. These three items were dropped from the scale. Factor analysis on the 15-item scale confirmed the two factors. These factor analyses are shown in Table 5.8. The first factor contains six items assessing the dimensions of family support while the second is composed of

Table 5.8

FACTOR ANALYSES ON PSR SCALE
USING VARIMAX ROTATION WITH ORTHOGONAL SOLUTION

DIMENSION	ITEM NO.*	Factor				Factor	
		1	2	3	4	1	2
Friend Support	1	.09	.19	.35	.28	.12	.45
	2	.07	.24	.27	.35	.10	.46
	4	.09	.12	.57	.08	.13	.41
	6	.08	.35	.31	.23	.10	.54
	7	.00	.61	.02	.13	-.02	.47
	11	.04	.74	.22	.07	.02	.67
	15	.13	.12	.59	.03	.16	.40
	16	.11	.49	.35	.14	.12	.62
	18	.18	.22	.13	.50	.24	.39
Family Support	5	.84	.07	.01	.18	.85	.11
	8	.57	-.04	.00	.38	.62	.10
	10	.76	.06	.24	.09	.77	.17
	12	.69	.04	.30	.01	.68	.24
	14	.52	.07	.06	.13	.52	.12
	17	.89	.17	.01	.09	.88	.09
Dropped	3	.10	.10	-.07	.36	---	---
From	9	.09	-.00	.17	.48	---	---
Scale	13	.06	.05	.06	.46	---	---

*Item No. refers to the order in which the items were originally administered.

Table 5.9

COMPONENT ITEMS AND STANDARDIZED ITEM ALPHAS
FROM TWO SAMPLES ON PSR SCALE

CONSTRUCT	ITEMS	Physical Disability (N = 827)	Mental* Health (N = 492)
Family Support (6 items)	No matter what happens, I know that my family will always be there for me should I need them. Sometimes I'm not sure if I can completely rely on my family. My family lets me know they think I'm a worthwhile person. People in my family have confidence in me. People in my family provide me with help in finding solutions to my problems. I know my family will always stand by me.	.87	.87
Friend Support (9 items)	When I'm with my friends I feel completely able to relax and be myself. I share the same approach to life that many of my friends do. People who know me trust me and respect me. When I want to go out to do things I know that many of my friends would enjoy doing these things with me. I have at least one friend that I could tell anything to. People who know me think I am good at what I do. My friends would take the time to talk over my problems, should I ever want to. Even when I am with my friends I feel alone. I feel very close to some of my friends.	.75	.80
Summary (15 items)		.82	.86

*Source: Turner et al., in press

nine items addressing friend support. Tests of the internal consistency of the family support and friend support factors and on the 15-item summary measure indicated satisfactory reliability. The component items of each dimension, and the alpha coefficients from this study and a study of ex-psychiatric patients are shown in Table 5.9.

Despite the inability of the PSR to reliably measure all of the "provisions of social relationships" specified by Weiss (1974), it appears to represent a reliable and promising instrument for assessing social support. Moreover, in providing a reasonable distinction between family support and friend support, the two clear subscales that have emerged provide an opportunity to consider the significance of source of support.

In sum, the Revised Kaplan Scale and the PSR Scale comprise the measures of social support that are used in this study. The summary scores of each of these measures will be used in analyses to provide indicators of overall support. An assessment of support available from two distinct sources - family and friends - will be provided by the subscales of the PSR. The two subscales of the Revised Kaplan Scale will be used in analyses as indicators of different types of support.

5.11. Coping Index and Coping Problems.

The coping index was developed for use in this study and was pre-tested on a small sample of physically disabled

adults. Respondents were asked to describe a problem or worry that they experienced because of their health condition, and to indicate on a coping checklist what they did to deal with the problem.

Two forms of a coping index were used in this study. In Form 1 respondents were asked if they had experienced a stressful situation related to their disability in the past six months. If the response was affirmative, respondents were asked to describe the most stressful situation they had experienced, and then to describe, on a four-point scale ranging from "never" to "always or most of the time" how often they used each coping strategy to deal with the problem.

One hundred seventy nine respondents were given this form of the coping index. One hundred of these respondents stated they had experienced no stressful situations related to their disability in the last six months. It was thought that the high proportion of respondents reporting no stressful situations might be an artifact of the wording of the question. Consequently the coping index was modified, and the second version, Form 2, was employed with the subsequent 817 respondents. Because of the changes made to both the question concerning stressful situations and the coping response scale, the two forms of the coping index are not readily comparable. Therefore analysis will be presented only on the Form 2 data, and further discussion of the coping measures is based on the Form 2 measure. The

Form 1 coping index is shown at the end of Appendix A.

5.11.1 Health Related Problems. Respondents were asked to describe the most difficult problem or worry they had experienced because of their health condition in the last year. Open-ended responses were then coded into categories describing the general context of the problem. These categories allow for the examination of the relationship between situational factors and types of coping responses, and psychological health status.

The following categories were established for classification of health related problems:

1. Work was defined as paid employment or school. This category includes concerns about the capacity to do one's present work or remain in school, being unable to work or study, and being unable to find employment.
2. Financial problems. Often this is associated with work problems but classification in the financial category occurs when financial problems are stated as the primary concern.
3. Family includes concerns with one's ability to perform family roles adequately, communication and interaction with family members, and concerns with the stress placed on family members by the disabled respondent.
4. Daily living is a broad category that includes concerns about performing tasks of daily living such as housework and shopping, transportation, housing, and household help.
5. Social concerns include problems of social interaction,

social isolation, and restrictions in social activities.

6. Self-care includes concerns about being able to perform self-care activities such as dressing and toiletry, concerns over lack of physical independence, and worry over increased incapacitation in the future.

7. Health covers a broad range of concerns, including a global concern with the disabling condition, pain, symptoms, medical treatments, and survival.

8. Other. This category includes problems that could not be included in any of the other categories, and were of a low frequency such that they did not warrant formation of a separate category.

After describing a problem the respondent was asked to rate the stressfulness of the problem on a seven-point scale ranging from "somewhat stressful" to "very stressful."

5.11.2. Non-Health Related Problems. If respondents stated they had had no health-related problems in the past year, they were then asked to describe the most stressful problem they had experienced in the last year. This approach allows for analysis of individuals coping strategies, and comparison of strategies for health and non-health problems.

Non-health problems were coded according to the classification scheme used for health problems, with two exceptions. Self-care problems were not applicable and were not included, and health problems refer to the health

of persons other than the respondent.

The stressfulness of the problems were rated on a seven-point scale, ranging from "somewhat stressful" to "very stressful."

5.11.3. The Coping Checklist. After describing a problem or worry, whether health related or not, the respondent completed the coping checklist. This is a twenty one item scale that describes a range of behavioral and cognitive coping strategies an individual might use to deal with a specific problem or worry. The checklist is binary, yes or no, and is always answered with a specific problem or worry in mind. Some of the items were derived from earlier coping scales (Pearlin and Schooler, 1978; Folkman and Lazarus, 1980; Weisman and Worden, 1976) and others were developed specifically for use in this study. This study provides no adequate basis for assessing the validity of this coping measure.

Factor analysis, calling for a varimax rotation, with an orthogonal solution, produced six factors with eigenvalues greater than one. Tests of internal consistency were done on the factor scales. One two-item factor, in which the two items correlated weakly ($r=.27$) was dropped. One item was dropped from a second two-item factor, and the other item was moved to another scale. Two other items were dropped because of their low correlations with their respective scales ($r<.20$). The final coping checklist consists of 16 items arrayed across four factors: a six-item

Table 5.10

COMPONENT ITEMS AND STANDARDIZED ITEM ALPHAS
ON THE COPING RESPONSE SCALE

CONSTRUCT	ITEMS	ALPHA
Minimize (6 items)	Accept the situation because there was nothing you could do about it. Go on as if nothing happened. Keep yourself busy with other things. Try not get too serious about-- laugh it off. Do something that you didn't think would help but at least you were doing something. Try to forget it -- put it out of your mind.	.77
Problem Focused (4 items)	Bargain or compromise to get something from the situation. Come up with a couple of different solutions to the problem. Concentrate on something good that could come out of the situation -- look for the silver lining. Make a plan of action and follow it.	.71
Emotional Support (4 items)	Turn to a friend or relative for advice. Get professional help and do what was recommended. Tell yourself things that helped you to feel better. Sit down and talk things out with the other people involved.	.62
Positive Comparisons (2 items)	Remind yourself that things could be a lot worse. Remind yourself that you were a lot better off than some people.	r=.38
Summary (16 items)		.83

dimension assessing coping through minimization of problems; a four-item dimension of problem focused coping, a four-item dimension assessing coping in terms of emotional support, and a two-item dimension assessing coping through the use of positive comparisons. The component items of each dimension, and alpha coefficients for each dimension, and a summary measure, are shown in Table 5.10. All alphas demonstrate satisfactory internal reliability.

The alpha coefficients are calculated on 575 cases. The considerable drop in sample size is due to a variety of sources. First, 179 of the total sample did not receive this coping index as part of their interview. Second, respondents who gave "no response" to five or more of the sixteen coping items used in the scale were dropped from analyses. Third, a small percentage of respondents reported they had experienced no problems in the last year and therefore they did not complete the coping index. Despite the large number of missing cases on this variable, the sample size remains sufficient for all analyses.

5.12. Functional Status

Functional status was assessed through an activities of daily living (ADL) scale. An ADL scale was developed for use in this study. The scale was designed to be applicable for non-hospitalized disabled persons, and suitable for self-response. The scale was intended to assess the

Table 5.11COMPONENT ITEMS AND STANDARDIZED ITEM
ALPHAS ON ACTIVITIES OF DAILY LIVING SCALE

CONSTRUCT	ITEMS	ALPHA
Self Care (5 Items)	able to feed self able to dress self able to use the toilet able to bathe self able to brush and comb hair	.74
Mobility (4 items)	able to move in and out of bed, chair able to walk able to walk upstairs able to walk downstairs	.81
Summary (9 items)		.80

domains of daily living included in other scales (c.f., Katz et al., 1970; Scranton et al., 1970) and to measure performance in three distinct areas: self-care activities, such as eating and dressing; mobility; and daily living activities, such as shopping and cooking meals.

Respondents were asked to rate how easily they could do each of the fifteen activities on a five-point scale ranging from "easily" to "need special equipment" to "completely unable to do this." Examination of the frequency distribution of this scale showed extremely low variation. While scores could range from 15 to 75, the median score was 18, and 80 percent of respondents scored 26 or less, indicating that a majority of the sample could perform most tasks easily or with only some difficulty. Consequently, it was decided to assymetrically collapse the five response categories into only two categories. Respondents who could perform the activity easily formed one category while respondents who experienced one of four degrees of difficulty with the activity were put in the second category. Higher scores indicate greater problems with the activities of daily living.

The daily living items, and two items dealing with car driving and use of public transportation were dropped from the scale because of excessive missing data.

Thus the ADL scale used here is a nine-item scale consisting of five items assessing self-care activities and four items assessing mobility. A nine-item summary measure

will be used in analysis as this is likely to provide the best indicator of functional status. Table 5.11 shows the component items and the alpha coefficients for each subscale and the summary measure. Alpha coefficients indicate a satisfactory level of internal consistency.

5.13. Stressful Life Events

Stressful life events are assessed through a modified version of an index developed for use in the Canada Health Survey (Statistics Canada, 1981). The 21-item scale includes items common to many life events scales (c.f., Holmes and Rahe, 1967). The reliability and validity of this particular scale have not been formally assessed. Subjects are asked to indicate each event that they or a family member experienced in the last year. Weights for each event are determined by subjects' rating of their personal experience of the event as "not at all stressful", "somewhat stressful" or "very stressful."

5.14. Statistical Analysis

The principal methods of statistical analysis to be used in this study are Pearson correlations and multiple regression.

The Pearson correlation provides a measure of the strength of the linear relationship between two variables. The correlation may range from -1.0 to +1.0. Correlation coefficients close to 0 indicate little or no linear

relationship between the two variables in question, while correlation coefficients close to -1 or +1 indicate strong linear relationships. Positive coefficients indicate a tendency for the two variables to increase together. Negative coefficients indicate that larger values of one variable are associated with smaller values of the second variable.

Multiple regression is a statistical technique that can be used to summarize or decompose the linear dependence of one variable on others. It is a particularly useful technique for evaluating the contribution of a specific variable or set of variables while simultaneously controlling for the effect of other factors.

This technique also allows for an evaluation of interactive effects, whereby the effect of one independent variable depends on the value of another independent variable. In this study, where interaction terms were included in regression analyses, they were forced into the regression equations after the main effects. Interaction terms are reported in the regression tables only if they attained significance at $p \leq .05$, when interaction terms are not statistically significant only the main effects are presented in the tables.

CHAPTER 6

RESULTS

6.1. Introduction

Analyses pertaining to each of the three research questions stated in Chapter 5 will be presented and discussed separately. The results concerning psychological distress will be presented first, and discussion of relationships with self-esteem will be presented in a separate section.

All analyses have been conducted with the total sample and not within specific disability subgroups. Several factors support the decision to conduct analyses on the sample as a single disability group. First it can be argued that while there may be variations in the relationships of interest across disability subgroups, it is also important to understand these relationships among the disabled as a whole. Second, small sample sizes within a majority of the disability categories would preclude reliable statistical analyses. Third, calculations showed that, for virtually all of the main relationships to be examined here, the correlations for the nine individual disability groups were estimates of the same population correlation (see Table 1 in Appendix C). This suggests that analyses on the total sample will not suppress important group variations and will provide a reliable

assessment of what is true for persons with a wide range of disabilities.

Before turning to the research questions the sample will be described in terms of demographic and several disability related characteristics. Sample distributions on some of the scales used in analyses will also be discussed. All relevant tables appear in Appendix C.

6.1.1. Demographic Characteristics. The age of study respondents ranged from 18 to 92 years. Approximately one third of the sample was between 18 and 49 years of age, one third was between 50 and 64 years, and one third was 65 years or more. The age distribution of the sample reflects the increased prevalence of physical disability among older populations (Allan, 1976; DHEW, 1981; Statistics Canada, 1981). The mean age of the sample is 56.4 years and the median age is 59.23 years. Complete data on the age distribution of the sample is shown in Table C.2.

Females comprise a slightly larger proportion of the sample (53.9%) than do males (46.1%). While previous research has found a higher prevalence rate of disability among women (Allan, 1976; DHEW, 1981; Statistics Canada, 1981), prevalence rates cannot be derived from these data. The sex distribution that was observed may be a function of the greater proportion of women in older age groups, where disability is most prevalent.

The majority of the sample was married (64.4%). Less than 10 percent had never been married and almost 25

percent reported marriages ending in widowhood, divorce or separation. The distribution of the sample according to marital status is presented in Table C.3.

A majority of respondents lived in urban areas (61.1%) with only 38.9 percent living in rural areas. As the sampling procedures were designed to obtain approximately this urban/rural ratio, these percentages do not provide an accurate description of the distribution of disabled persons by residence. When the effects of the sampling procedures are controlled, and both participants and lost cases are considered it appears that approximately 18 percent of disabled adults in Southwestern Ontario are rural residents and 82 percent reside in urban areas.

The distribution of the sample on annual household income is shown in Table C.4. Thirteen percent of respondents reported incomes of less than \$5,000 and 57 percent reported incomes under \$15,000. Only 18 percent of the sample had household incomes over \$25,000.

Thirty five percent of those who lived alone, compared with 8 percent of those who lived with others, had annual household incomes under \$5,000. With an annual income of \$5,450 or less for a single person representing the poverty level in 1980, 27 percent of single persons in Ontario lived in poverty (National Council of Welfare, 1982). Thus disabled persons living alone are at elevated risk for poverty, in comparison with the general population. In this sample the median income of persons living alone was

between \$5,000 and \$9,999 and for those living with others, it was between \$10,000 and \$14,999. Statistics Canada (1978) reported a median income of \$7,141 for individuals and \$21,105 for families in Ontario in 1978. Given the likely increase in these median incomes since 1978, it is clear that disabled persons have substantially lower incomes than the general population.

It should be noted however, that neither the income distribution of respondents in this study nor the statistics reported for the general population have been adjusted for age. Given the large percentage of respondents over age 65 in this sample, and the generally lower incomes of persons over age 65, it may be that this sample is not as seriously disadvantaged, in terms of income, relative to the general population, when adjustments for age are made. No age-adjusted data on income of the general population were available to make these comparisons.

Table C.5 presents data on the distribution of the sample by level of education. Thirty eight percent of respondents had 8 or fewer years of education, and 55 percent reported from 1 to 4 years of high school education. Seven percent of respondents attended university for one or more years. The median level of education for the total sample was 9.7 years. In 1971, the median level of schooling for Ontario adults was 9.6 years (Statistics Canada, 1971). While the median level of schooling may

have increased somewhat since 1971, this sample does not appear to be substantially disadvantaged in terms of schooling, relative to the general population.

Data on employment status of the sample are shown in Table C.6. Twenty eight percent of the total sample were retired and 24 percent were homemakers. Among persons under 65 only 38 percent of males and 13 percent of females were employed full time. Thirty one percent of males and 25 percent of females under 65 were unemployed. This compares with unemployment rates of 5.6 percent for males and 7.8 percent for females of all ages in Ontario in 1979 (Statistics Canada, 1979). The high rate of unemployment in this sample is consistent with other studies that have found elevated rates of unemployment among the disabled (c.f., Brown, 1977).

6.1.2. Disability Related Characteristics. Complete data on the distribution of the sample within disability categories by age and sex are shown in Table C.7. This table reports on the major disabling condition of respondents. Secondary disabling conditions were reported by 50 percent of respondents.

For ten percent of respondents age of disability onset was 17 years or younger. Age of onset was between 18 and 44 years for 38 percent of respondents and between 45 and 64 years for another 38 percent of the sample. Only 12 percent of respondents reported onset after age 65. The mean duration of disabling conditions was 13.67 years.

In general, respondents reported that their conditions were serious. Sixty four percent of the sample reported that they were very much limited in their activities because of their disabling conditions. Only 6 percent of the sample stated that their activities were not limited very much because of their disabilities. Twenty two percent of respondents perceived their disabilities as very severe and 65 percent rated their conditions as severe or somewhat severe. Only 11 percent of respondents felt their conditions were not very severe or not at all severe. The distribution of the sample on activity limitations and perceived severity of disability are presented in Tables C.8 and C.9, respectively.

Functional status was assessed through a 9-item activities of daily living scale. Thirty one percent of respondents reported that they could perform all the self-care and mobility activities easily. Forty percent of respondents had difficulty with one to three of the nine activities and twenty nine percent had difficulty performing four or more of the activities.

6.1.3. Sample Distributions on Selected Scales.

Statistics relevant to the sample distributions on the PSR Scale, the Revised Kaplan Scale, the general distress scale, the life events stress scale and the coping index are presented in Tables C.10 through C.14, respectively.

The distribution of the sample on the CES-D Scale will be discussed in greater detail, as normative data are

available for comparisons. For the total sample the mean score on the CES-D was 14.13. The mean score for males was 12.32 and for females it was 15.65. A score of 16 or higher is generally considered the cut off point for identifying a clinically significant level of depressive symptomatology, and in general population samples approximately 20 percent of respondents will have scores of 16 or more (Comstock and Helsing, 1976). Thirty five percent of this sample scored 16 or higher. This suggests that the present sample contains a substantially higher percentage of depressed individuals than would be expected in the general population. Other sample statistics on the CES-D Scale are presented in Table C.15.

6.2. Additional Variables To Be Considered in Analyses

In addition to the three main classes of variables - social support, coping, and psychological adjustment - several other variables are included in certain analyses. Five variables have been designated for use as statistical control variables. These variables were selected on the basis of their theoretical and empirical relevance in relation to psychological adjustment.

Age and sex will be controlled in all analyses. Previous research has shown a significant relationship between sex and psychological distress. Higher rates of depression among women have been consistently observed (c.f., Aneshensel et al., 1981; Gove and Geerken, 1977).

Age has also been significantly associated with various dimensions of psychological distress, although findings on the direction of the relationship have not been consistent. While several studies have suggested that depression is more prevalent in younger age groups (c.f., Comstock and Helsing, 1976; Radloff, 1980) other studies have reported that depression is a serious problem among the aged (c.f., Gurland, 1976; Schwab et al., 1973).

Three disability related variables have been selected for use as control variables. While the literature has not shown a consistent relationship between any disability related variables and psychological distress, some research has suggested that certain of these variables are positively associated with psychological distress (c.f., Alexander et al., 1979; Earle et al., 1979; Zahn, 1973). The variables to be controlled in these analyses are: 1) duration of disability; 2) perceived severity of disability; 3) functional status. Duration of disability is measured by the number of years since disability onset. Perceived severity of the disability was assessed through subjects' ratings of their conditions on a five-point scale ranging from "very severe" to "not at all severe." An activities of daily living scale that evaluated respondents' mobility level and ability to perform self-care activities was used to assess functional status.

Previous research has indicated that there is a significant relationship between life events stress and

psychological distress, such that persons who have experienced a greater number of life events, within a given time period, are likely to subsequently experience greater psychological distress than are persons who have experienced fewer life events (c.f., Barret, 1979; Mueller et al., 1977; Vinokur and Selzer, 1975).

Other research has suggested that life stress plays an important role in the relationship between social support and psychological distress. Several studies have indicated that social support is associated with psychological distress primarily through its role as a buffer against the effects of life events (c.f., Brown et al., 1975; Gore, 1978; Pearlin et al., 1981). Given the theoretical and empirical importance of life stress to both psychological distress and the social support/psychological distress relationship, life stress is incorporated as a variable in certain analyses.

6.3. Basic Relationships Between Psychological Distress and Selected Variables

A correlation matrix including the five control variables, life stress, and the measures of psychological distress and social support is presented in Table 6.1. Examination of the pattern of coefficients among components of the PSR Scale and the Revised Kaplan Scale suggests considerable cohesiveness both within and across the two scales. The correlation between the summary measures of the PSR and

Table 6.1
ZERO-ORDER CORRELATIONS BETWEEN MEASURES OF SOCIAL SUPPORT,
PSYCHOLOGICAL DISTRESS, STRESS AND CONTROL VARIABLES

	(1)	(2)	(3)	(4)	(5)	(6)	(7)	(8)	(9)	(10)	(11)	(12)	(13)	(14)
(1) PSR SUMMARY	--													
(2) PSR FAMILY	.79*	--												
(3) PSR FRIENDS	.83*	.31*	--											
(4) REVISED KAPLAN	.62*	.45*	.55*	--										
(5) LOVE/ESTHER-KAPLAN	.60*	.45*	.51*	.93*	--									
(6) NETWORK-KAPLAN	.47*	.32*	.46*	.84*	.59*	--								
(7) CES-D	-.38*	-.31*	-.31*	-.31*	-.28*	-.26*	--							
(8) GENERAL DISTRESS	-.35*	-.25*	-.31*	-.27*	-.26*	-.22*	.83*	--						
(9) AGE	.08*	.08*	.03	-.02	.03	.08*	-.07*	-.19*	--					
(10) SEX ¹	.002	-.03	.03	.01	.05	-.06*	.14*	.12*	-.002	--				
(11) PERCEIVED SEVERITY?	.01	.01	.03	-.02	-.04	.01	.23*	.17*	.08*	.08*	--			
(12) DURATION	.01	.04	-.02	-.04	-.01	-.07*	-.12*	-.10*	.18*	.002	-.05	--		
(13) FUNCTIONAL STATUS	-.05	.002	-.08*	.002	.03	.04	-.20*	-.12*	-.18*	.07*	.30*	-.07	--	
(14) STRESS	-.14*	-.16*	-.07*	-.04	-.03	-.04	.33*	.37*	-.29*	.14*	.08*	-.11*	.03	--

*p < .05

1 coded 1 = male, 2 = female

2 coded 1 = not at all severe, 5 = very severe

3 coded higher scores = better functional status

Revised Kaplan Scales indicates less than 40 percent of the variance is shared by these scales, suggesting that the two scales measure the same construct without noteable redundancy.

As can be seen all indices of social support are significantly associated with the psychological distress measures. The summary measure of the PSR Scale shows somewhat stronger correlations with both distress measures than does the summary measure of the Revised Kaplan Scale, and this is generally true of the subdimensions as well. The correlations with the subdimensions of both support scales show a pattern that is consistent with the summary measures and the subscales do not appear to provide information beyond that found with the summary measures.

Life stress shows moderate relationships with the measures of psychological distress, with higher levels of life stress associated with greater psychological distress. Low but significant correlations between stress and the PSR Scale and its subdimensions are found. No significant relationship between stress and any of the Revised Kaplan measures is observed.

An examination of the control variables shows low but significant correlations between age and sex and each of the psychological distress measures. Greater psychological distress is associated with younger age and being female. Each of the three disability related variables shows weak associations with the psychological distress measures, and

the correlations are in the expected direction. Lower levels of psychological distress are associated with a perception of one's disability as less severe, and better functional status. Longer duration of disability is also associated with lower levels of psychological distress, suggesting that some adaptation may occur over time. The correlations between the control variables and the social support measures are generally non-significant. The few significant correlations that are observed tend to be weak and overall these correlations indicate that there are no important relationships between these variables.

6.4. The Significance of Social Support for Psychological Distress

6.4.1. Analyses of the Subdimensions of the PSR Scale and the Revised Kaplan Scale. Thus far it has been shown that the subdimensions of both the PSR Scale and the Revised Kaplan Scale are significantly associated with psychological distress. To examine in more detail whether certain sources of support or types of support are particularly important for psychological distress multiple regression analyses with the subdimensions of the two social support scales were done. Tables 6.2 and 6.3 show the results of multiple regression analyses where the depression and the general distress measures were regressed on the social support subdimensions and the control variables.

Table 6.2

Multiple Regression Analysis of the CES-D Scale on
the PSR Scale and Revised Kaplan Scale
Subdimensions and Control Variables

Variables	Unstandardized Regression Coefficient	Standard Error	Standardized Coefficient	R ²
Age	-.047*	.023	-.069	.006
Sex	3.408***	.731	.149	.027
Perceived Severity	2.220***	.399	.187	.076
Duration	-.010***	.027	-.120	.090
Functional Status	-.575***	.178	-.110	.103
PSR Family	-.381***	.084	-.165	.189
Network - Kaplan	-.297	.152	-.078	.223
PSR Friends	-.335***	.085	-.151	.248
Love/Esteem - Kaplan	-.329**	.117	-.122	.255

F=28.44 ***p≤.001, **p≤ .01, *p≤.05 N=756

Table 6.3

Multiple Regression Analysis of General Distress
on the PSR Scale and Revised Kaplan Scale
Subdimensions and Control Variables

Variables	Unstandardized Regression Coefficient	Standard Error	Standardized Coefficient	R ²
Age	-.026***	.005	-.179	.033
Sex	.644***	.163	.130	.048
Perceived Severity	.412***	.089	.160	.081
Duration	-.013*	.006	-.073	.085
Functional Status	-.067	.040	-.059	.090
PSR Family	-.050**	.019	-.010	.143
Network - Kaplan	.050	.034	-.061	.174
PSR Friends	-.088***	.019	-.184	.207
Love/Esteem - Kaplan	-.065*	.026	-.111	.213
<hr/>				
F=22.48	***p≤.001, **p≤.01, *p≤.05			N=756

It can be seen that both PSR subdimensions and the love/esteem dimension of the Revised Kaplan Scale are significantly associated with both depression and general distress. The network dimension fails to attain significance in either regression equation. All of the control variables show significant associations with both measures of psychological distress, with the exception of functional status, which is significantly related only to depression.

Overall these analyses suggest that the PSR subdimensions are somewhat stronger predictors of psychological distress than are the Revised Kaplan subdimensions. However from these analyses it does not appear that the subdimensions supply any important additional information. In the remainder of analyses only the summary measures of the PSR Scale and the Revised Kaplan Scale will be used as they are likely to provide the most concise and useful estimates of experienced social support.

6.4.2. Summary Measures of Social Support and Their Relationship with Psychological Distress. The CES-D and the general distress measure were each regressed on the summary measures of the PSR Scale and the Revised Kaplan Scale and the control variables. The results are shown in Tables 6.4. and 6.5. The Revised Kaplan Scale and the PSR Scale are each associated with depression and with general distress, independent of the effects of age, sex, duration of disability, perceived severity of disability, and

Table 6.4

Multiple Regression Analysis of the CES-D Scale
on the PSR Scale, The Revised Kaplan Scale
and Control Variables

Variables	Unstandardized Regression Coefficient	Standard Error	Standardized Coefficient	R ²
Age	-.048*	.023	-.069	.006
Sex	3.409***	.723	.150	.027
Perceived Severity	2.220***	.398	.187	.076
Duration	-.010***	.027	-.121	.090
Functional Status	-.567***	.176	-.109	.103
Revised Kaplan Scale	-.313***	.071	-.177	.214
PSR Scale	-.359***	.056	-.258	.255
<hr/>				
F=36.63	***p \leq .001, *p \leq .05		N=756	

Table 6.5

Multiple Regression Analysis of General Distress
on the PSR Scale, The Revised Kaplan Scale
and Control Variables

Variables	Unstandardized Regression Coefficient	Standard Error	Standardized Coefficient	R ²
Age	-.027***	.005	-.178	.033
Sex	.627***	.161	.127	.048
Perceived Severity	.408***	.089	.158	.081
Duration	-.013*	.006	-.071	.085
Functional Status	-.071	.039	-.063	.090
Revised Kaplan Scale	-.061***	.016	-.159	.179
PSR Scale	-.069***	.012	-.230	.211
<hr/>				
F=20.64	***p≤.001, *p≤.05		N=756	

functional status, and independent of each other.

It is interesting to observe that both the PSR Scale and the Revised Kaplan Scale enter into the regression equations, despite the high correlations between the two scales ($r=.62$). Since both social support measures make significant and independent contributions to psychological distress, indicating that each contains some unique variance, it seemed important to consider both measures. In the service of parsimony and to aid in the interpretation of findings a single summary measure of social support was created. Scores on the PSR Scale and the Revised Kaplan Scale were standardized to achieve equal weighting and the two scales were then summed. This summary measure of social support is used in the remainder of analyses.

Tables 6.6 and 6.7 present the results of regression analyses where the depression and general distress measures were each regressed on the standardized social support measure and the control variables. Looking first at the control variables it can be seen that perceived severity of the disability is significantly associated with both psychological distress measures, and it is the strongest predictor of any of the disability related variables. Duration also shows a significant, but weaker effect on both psychological distress measures. While the zero order correlations showed functional status was significantly associated with both measures of psychological distress, once the effects of other variables are controlled a significant

Table 6.6

Multiple Regression Analysis of the CES-D Scale
on Social Support and Control Variables

Variables	Unstandardized Regression Coefficient	Standard Error	Standardized Coefficient	R ²
Age	-.049*	.023	-.071	.006
Sex	3.410***	.724	.150	.027
Perceived Severity	2.241***	.398	.188	.076
Duration	-.101***	.027	-.122	.089
Functional Status	-.580***	.176	-.111	.102
Social Support	-2.524***	.205	-.390	.254

F=42.56

***p \leq .001, *p \leq .05

N=756

Table 6.7

Multiple Regression Analysis of General Distress
on Social Support and Control Variables

Variables	Unstandardized Regression Coefficient	Standard Error	Standardized Coefficient	R ²
Age	-.027***	.005	-.180	.033
Sex	.627***	.161	.127	.048
Perceived Severity	.411***	.089	.160	.081
Duration	-.013*	.006	-.072	.085
Functional Status	-.073	.040	-.065	.089
Social Support	-.489***	.046	-.348	.210
<hr/>				
F=33.30	***p≤.001, *p≤.05		N=756	

relationship is observed only for depression. Age and Sex show significant relationships with both measures of distress.

Variations in duration and perceived severity of the disability and functional status are of minimal significance for psychological distress among the disabled. Social support is clearly the strongest predictor of both depression (standardized coefficient = $-.390$) and general distress (standardized coefficient = $-.348$). Examination of the cumulative R^2 shows that when the effects of the other variables, in the equations are controlled, social support accounts for 15 percent of the explained variance in depression and 12 percent of the explained variance in general distress. Social support is somewhat more strongly associated with depression than with general distress, a finding that is consistent with some previous research (c.f., Brown et al., 1975; Dean et al., 1981; Miller and Ingham, 1976). This set of variables explains 25 percent of the variance in depression and 21 percent of the variance in general distress.

This study involved the use of stratified multi-stage clustering sampling and at this point it is necessary to discuss the implications of this sampling technique for data analysis. While stratification tends to reduce sampling errors and cluster sampling generally increases sampling errors, the two effects do not typically cancel each other out. The stratification often results in little

gain while multi-stage clustering tends to increase variances substantially. The net effect is that the standard errors of estimators derived from stratified multi-stage cluster sampling are generally greater than those that would be obtained through simple random sampling; in other words, the design effect factor is usually greater than one.

The standard error of the regression coefficients that have been reported in these analyses were computed by means of a formula for estimating standard errors when simple random sampling has been done. Thus these standard errors are likely to slightly underestimate the true standard errors of the estimators among this sample. While the effect of cluster sampling on standard errors of regression coefficients has been found to be smaller than the effect on many other statistics (Kish and Frankel, 1968) the underestimation of these standard errors may have important implications for the statistical significance of the regression coefficients.

In consideration of the design effect factor an adjustment was made to the standard error of the social support measure that was reported in Tables 6.6 and 6.7. The standard error was increased by an inflation factor of 10 percent. The factor was chosen on the basis of discussion of this issue by Moser and Kalton (1971). The statistical significance of the newly calculated R-statistics was then tested. In both the depression and

general distress regressions social support remained statistically significant at $p \leq .001$.

Adjustments to the standard errors of the other variables were not made as these variables are employed as control variables, and their statistical significance is not of critical importance to the research questions that are addressed in these analyses.

6.4.3. Social Support, Life Stress and Psychological Distress. Thus far it has been shown that social support plays a significant role in psychological distress among the disabled and that this is independent of the influence of several disability related variables. The role of life stress in the social support/psychological distress relationship will now be examined and the question of whether social support has main effects on psychological distress or is largely associated with distress through its role as a buffer against the effects of life stress will be addressed.

Multiple regression analyses were employed to examine the joint and independent effects of social support and stress on psychological distress. A support x stress interaction term was entered into these analyses. A significant interaction term would be consistent with the hypothesis that the influence of social support on psychological distress is a function of life stress level. The absence of a significant interaction term would be inconsistent with this hypothesis and would suggest that the

Table 6.8

Multiple Regression Analysis of the CES-D Scale
on Social Support, Stress and Control Variables

Variables	Unstandardized Regression Coefficient	Standard Error	Standardized Coefficient	R ²
Perceived Severity	1.841***	.403	.154	.038
Duration	-.096***	.027	-.113	.057
Sex	2.860***	.734	.125	.088
Age	.0007	.024	.001	.092
Functional Status	-.519**	.180	-.099	.105
Social Support	-2.297***	.207	-.352	.249
Stress	.462***	.060	.250	.304

F=43.65

***p \leq .001, **p \leq .01

N=706

Table 6.9

Multiple Regression Analysis of General Distress
on Social Support, Stress and Control Variables

Variables	Unstandardized Regression Coefficient	Standard Error	Standardized Coefficient	R ²
Perceived Severity	.320***	.089	.123	.021
Duration	-.012*	.006	-.068	.035
Sex	.514**	.164	.103	.058
Age	-.016**	.005	-.105	.088
Functional Status	-.061	.040	-.053	.093
Social Support	-.436***	.046	-.307	.206
Stress	.107***	.014	.268	.269

F=36.83 *** $p \leq .001$, ** $p \leq .01$, * $p \leq .05$ N=706

effects of social support and life stress on psychological distress do not modify each other.

Table 6.8 shows the results of analyses where the CES-D was regressed on social support, stress, a support x stress interaction term and the control variables. The support x stress interaction term was not significant at $p \leq .05$, and therefore only the main effects are presented in the table. As can be seen, social support, stress, sex and each of the disability related variables show significant and independent associations with depression. Social support is clearly the strongest predictor of depression (standardized coefficient = $-.352$). While stress shows a moderate relationship with depression (standardized coefficient = $.250$), the disability related variables each show considerably weaker associations.

This regression analysis was repeated with the general distress measure as the dependent variable, and the results are shown in Table 6.9. Only the main effects are shown as the support x stress interaction term did not attain significance at $p \leq .05$. Social support and stress are again the strongest predictors. Age, sex, perceived severity and duration of disability are all significantly associated with general distress but their relationships are substantially weaker. Functional status is not significantly associated with general distress.

In consideration of the effect of stratified multi-stage cluster sampling discussed earlier, adjustments were

made to the standard errors of the social support and stress measures, and tests of significance on the newly calculated F-statistics showed that in the regressions of both psychological distress measures, social support and stress remained statistically significant at $p \leq .001$.

In terms of whether social support has main versus buffering effects these analyses suggest that there are main effects involved in the social support/psychological distress relationship. There is a significant and substantial relationship between social support and psychological distress independent of the effects of life stress. The failure of the support x stress interaction term to attain significance suggests that some important part of the association between social support and psychological distress must be direct, rather than conditional on life stress level.

6.4.4. Sex Differences in the Relationship Between Social Support, Life Stress and Psychological Distress.

Based on the intuitively appealing hypothesis that the determinants of psychological distress may vary by sex, the relationship between social support and psychological distress, and the impact of stress level on that relationship were examined separately for men and women. Before turning to these relationships, sex differences on the variables of interest will be discussed. Table 6.10 presents and compares mean scores for males and females on these variables.

Table 6.10

ONE WAY ANALYSIS OF VARIANCE ON SELECTED
VARIABLES BY SEX

Variable	MALES		FEMALES		F
	N	Mean	N	Mean	
Social Support	378	.107	456	.075	.07
Stress	429	6.406	491	8.053	17.18***
CES-D	410	12.317	488	15.652	18.97***
General Distress	390	-.347	483	.249	12.85***
Age	456	56.417	533	56.350	.004
Perceived Severity	452	3.752	529	3.591	6.95**
Duration	455	13.687	531	13.647	.002
Functional Status	446	6.800	524	6.504	4.35*

*** $p \leq .001$, ** $p \leq .01$, * $p \leq .05$

As can be seen there are no differences on mean level of social support, duration of disability or age. However sex differences are observed on all other variables. Females show a significantly higher mean life stress level than do males, while males rate their disabilities as slightly more severe than do females. Females have a significantly lower score on the measure of functional status than do males, indicating poorer functional status among women.

Clear differences are observed on both measures of psychological distress, with females experiencing higher levels. As noted earlier a score of 16 or more on the CES-D is generally considered the cut off point for identifying a clinically significant level of depression. Thirty nine percent of the females scored 16 or more, compared with 29 percent of the males. This is consistent with other research that has shown a higher rate of depression among women (c.f., Aneschensel et al., 1981; Comstock and Helsing, 1976).

To assess sex differences in the social support/psychological distress relationship, regression analyses were done separately for males and females. Results of these analyses are shown in Tables 6.11 and 6.12. An examination of the cumulative R^2 in each of these tables suggests that for both males and females, the independent variables explain more of the variance in depression than in general distress and that they explain a greater

Table 6.11

Multiple Regression Analysis of the CES-D Scale
on Social Support, Stress and Control Variables
for Males and Females

Variables	Unstandardized Regression Coefficient	Standard Error	Standardized Coefficient	R ²	F	N
<u>MALES</u>						
Age	.026	.031	.041	.004		
Perceived Severity	1.676**	.538	.159	.055		
Duration	-.077*	.037	-.100	.066		
Functional Status	-.545	.229	-.119	.090		
Social Support	-2.422***	.290	-.396	.270		
Stress	.467***	.086	.271	.334	24.90	316
<u>FEMALES</u>						
Age	-.018	.035	-.025	.006		
Perceived Severity	2.035***	.594	.159	.055		
Duration	-.109**	.040	-.123	.073		
Functional Status	-.515	.270	-.090	.081		
Social Support	-2.214***	.293	-.333	.218		
Stress	.460***	.088	.241	.272	23.30	390

*** $p < .001$, ** $p < .01$, * $p < .05$

Table 6.12

Multiple Regression Analysis of General Distress
on Social Support, Stress and Control Variables
for Males and Females

Variables	Unstandardized Regression Coefficient	Standard Error	Standardized Coefficient	R ²	F	N
<u>MALES</u>						
Age	-.010	.008	-.066	.029		
Perceived Severity	.405**	.129	.163	.075		
Duration	-.010	.009	-.054	.078		
Functional Status	-.072	.055	-.068	.088		
Social Support	-.512***	.070	-.356	.234		
Stress	.114***	.021	.282	.303	22.20	316
<u>FEMALES</u>						
Age	-.019*	.007	-.129	.038		
Perceived Severity	.270*	.127	.102	.058		
Duration	-.015	.009	-.081	.067		
Functional Status	-.050	.058	-.043	.070		
Social Support	-.395***	.062	-.286	.174		
Stress	.101***	.019	.255	.233	19.13	390

***p<.001, **p<.01, *p<.05

proportion of the variance in both depression and general distress for males than for females.

As can be seen in Table 6.11 for both sexes social support and stress are significantly and independently associated with depression, and social support is the strongest predictor. Duration and perceived severity are significantly associated with depression for both sexes although perceived severity appears to be a stronger predictor of depression for women than for men. Functional status shows a significant association with depression only among males.

To test the significance of these observed sex differences, multiple regression was employed using sex as a dummy variable, and including interaction terms between sex and each of the independent variables. None of the interactions were significant, indicating that the differences between males and females that are observed in the separate regression analyses are not statistically significant.

Turning now to the regressions of general distress, a similar pattern is observed. Social support, stress and perceived severity show significant associations with general distress for both sexes. Duration and functional status are not significant for either sex, and age is not a significant predictor among males. Multiple regression analysis with sex as a dummy variable and employing interaction terms between sex and the independent variables again showed the apparent sex differences to be

non-significant. Thus although sex is related to both depression and general distress in that women show higher levels of distress, the significance of all independent variables considered was highly uniform across sex.

In none of the regression analyses done separately for males and females did the support x stress interaction term achieve statistical significance. The non-significant interaction term indicates that for both sexes the relationship between social support and psychological distress is direct, rather than conditional on life stress.

6.4.5. Summary. This section has considered the significance of social support for psychological distress among the physically disabled. Analyses showed both the PSR Scale and the Revised Kaplan Scale to be significantly and independently associated with psychological distress. The subdimensions of these scales were significantly related to psychological distress, and showed a pattern of association similar to that observed with the summary measures.

Of the variables considered, social support was clearly the strongest predictor of psychological distress among the disabled. The relationship between social support and psychological distress remained both statistically significant and substantial when the effects of life stress, age, sex and disability related variables were controlled.

On the question of whether social support is directly

associated with psychological distress or is important largely as a buffer of the effects of life stress, evidence was found only for direct effects. For the total sample, and for males and females considered separately social support showed a significant relationship with psychological distress, independent of the effects of life stress, and there was no indication of an interaction between social support and life stress.

For both males and females social support was strongly associated with psychological distress, and the pattern of association between the variables considered and psychological distress was not significantly different across the sexes.

6.5. Coping and Psychological Distress

Zero-order correlations between the two measures of psychological distress and the coping dimensions are presented in Table 6.13. No significant relationships are observed between the general distress measure and any of the coping measures. Significant but weak associations are found between depression and three coping subdimensions, and with the coping summary measure. As the coping subdimensions do not appear to make a noticeable contribution to an understanding of the relationship between coping and psychological distress, only the coping summary measure will be used in subsequent analyses. The negative correlations with the coping summary measure indicate that use

Table 6.13

ZERO-ORDER CORRELATIONS BETWEEN MEASURES OF
PSYCHOLOGICAL DISTRESS AND COPING

	Minimization	Emotional Support	Problem Focused	Positive Comparisons	Coping Summary
CES-D	.10***	.10***	-.03	.09*	-.11***
General Distress	-.06	-.07	.04	-.05	-.05

*** $p \leq .01$, * $p \leq .05$

of a larger number of coping strategies is associated with lower levels of psychological distress. The coping summary measure is a simple count of how many coping strategies the respondent used to deal with his/her problem, and thus provides an estimate of the range of one's coping repertoire. The value of a coping summary measure has been suggested by Pearlin and Schooler (1978:14) who have stated that "the sheer richness and variety of responses and resources that an individual can bring to bear in coping with life strains may be more important in shielding one's self from emotional stress than the nature and content of any single coping element."

To further assess the relationship between coping and psychological distress multiple regression analyses were carried out. The demographic and disability related control variables were included in analyses as they have been shown to be significantly associated with psychological distress. The results of these analyses are presented in Table 6.14 and 6.15. As can be seen, coping shows no significant relationship with general distress, and only a weak association with depression. Several of the control variables show stronger associations with the psychological distress measures than does the coping measure. When the effects of the other variables in the equation are controlled, coping contributes only 1 percent to the explained variance in depression.

An adjustment to the standard error of coping was

Table 6.14

Multiple Regression Analysis of the CES-D Scale
on Coping and Control Variables

Variables	Unstandardized Regression Coefficient	Standard Error	Standardized Coefficient	R ²
Age	-.049	.032	-.067	.0004
Sex	4.431***	1.016	.183	.026
Perceived Severity	-2.282***	.553	.180	.078
Duration	-.085*	.040	-.091	.090
Functional Status	.852***	.239	-.158	.111
Coping	-.479**	.186	-.108	.122
F=11.89 ***p<.001, **p<.01, *p<.05 N=518				

Table 6.15

Multiple Regression Analysis of General Distress on
Coping and Control Variables

Variables	Unstandardized Regression Coefficient	Standard Error	Standardized Coefficient	R ²
Age	-.030***	.007	-.195	.023
Sex	.698***	.215	.139	.038
Perceived Severity	-.368**	.117	.140	.068
Duration	-.006	.008	-.033	.071
Functional Status	.133**	.005	-.118	.083
Coping	-.072	.039	-.079	.088
<hr/>				
F=8.31	***p<.001, **p<.01		N=518	

made, in order to take the effect of stratified multi-stage cluster sampling into account. Tests of the significance of the newly computed F-statistic showed that coping remained significantly associated with depression at $p \leq .01$.

These analyses have shown only a weak association between coping and psychological distress. As psychological distress is likely to be associated with a wide array of factors, there may be no direct relationship between coping and distress; other factors may importantly condition this relationship. In the following sections two such factors are examined: the type of problem to be coped with and level of problem stress.

6.5.1. Variations Across Problem Categories. It may be that the relationship between coping and psychological distress varies with the type of life problem confronted by the disabled person. Respondents were asked to specify the nature of the problem and whether the problem was associated with their disabling condition. As only a small percentage of respondents reported non-health related problems, health and non-health related problems were combined. Zero-order correlations between coping and psychological distress within problem categories are shown in Table 6.16. As can be seen there is considerable variation in these relationships across problem categories. Coping is not significantly associated with either general distress or depression in the problem categories of work, finances,

Table 6.16

ZERO-ORDER CORRELATIONS BETWEEN MEASURES OF PSYCHOLOGICAL
DISTRESS AND COPING WITHIN PROBLEM CATEGORIES

PROBLEM CATEGORY	PSYCHOLOGICAL DISTRESS	COPING	
			N
Work	CES-D	-.09	100
	General Distress	-.08	96
Finances	CES-D	-.08	63
	General Distress	-.04	62
Family	CES-D	.03	82
	General Distress	.001	80
Social Problems	CES-D	-.29*	33
	General Distress	-.39*	33
Health	CES-D	-.03	134
	General Distress	.08	131
Daily Living	CES-D	-.28**	78
	General Distress	-.20	78
Self-Care	CES-D	-.41**	36
	General Distress	-.21	37

** $p \leq .01$, * $p \leq .05$,

health, and family. Moderate correlations between coping and both measures of psychological distress are found within the categories of social problems and daily living. The strongest correlation is found between coping and depression in the self-care activities category.

No consistent pattern is readily observed in these correlations. Pearlin and Schooler (1978) have suggested that in the more impersonal, less intimate areas of life the forces affecting people may be more resistant to coping efforts. They found that how one coped with strains in occupational and financial domains had relatively little impact on level of psychological distress, and the results of this study replicate their findings. Health may also be seen as an area in which people, particularly those with physical disabilities, have little control, and this may explain the absence of an association between coping and psychological distress in the health category. Pearlin and Schooler (1978) found that coping responses showed their greatest impact on psychological distress when the strains concerned more personal areas of life such as marriage and parenting. With the exception of the family category, the results of this study suggest that coping is more strongly associated with psychological distress when the problems to be coped with concern more intimate aspects of life.

One explanation for the failure to find a more consistent relationship between coping and psychological distress may be that the problem categories are too

heterogeneous. Within each problem category, there is a wide array of problems and this broad grouping may inhibit observation of some part of the relationship. However there were not enough instances of specific subcategories of problems to permit their separation for the purposes of analyses. Nonetheless, the significant correlations that are observed within problem categories are considerably stronger than the zero-order correlations shown in Table 6.13, where type of problem was not taken into consideration. This suggests that knowledge of the type of problem to be coped with does have some importance when evaluating the relationship between coping and psychological distress.

6.5.2. The Role of Problem Stress. Respondents rated the stressfulness of the problem to be confronted on a 7-point scale ranging from "mildly stressful" to "very stressful." To examine the role of problem stress in the relationship between coping and psychological distress, multiple regression analyses were carried out. The independent variables examined were coping, problem stress, a coping x problem stress interaction term, and the control variables. A significant interaction term may suggest that the effect of coping on psychological distress would be conditioned by problem stress level. The absence of a significant interaction term may indicate that the effects of coping and problem stress on psychological distress do not modify each other. Social support, although shown to be significantly associated with psychological distress,

Table 6.17

Multiple Regression Analysis of the CES-D Scale on Coping,
Problem Stress and Control Variables

Variables	Unstandardized Regression Coefficient	Standard Error	Standardized Coefficient	R ²
Age	-.030	.031	-.041	.0004
Sex	3.899***	.994	.161	.026
Perceived Severity	-1.650**	.552	.130	.078
Duration	-.073	.039	-.078	.090
Functional Status	.733**	.234	-.136	.111
Coping	-.436*	.181	-.098	.122
Problem Stress	1.593***	.298	.226	.169
F=14.83 ***p≤.001, **p≤.01, *p≤.05 N=518				

Table 6.18

Multiple Regression Analysis of General Distress on
Coping, Problem Stress and Control Variables

Variables	Unstandardized Regression Coefficient	Standard Error	Standardized Coefficient	R ²
Age	-.025***	.007	-.165	.023
Sex	.570**	.209	.113	.038
Perceived Severity	-.216	.116	-.082	.068
Duration	-.003	.008	-.018	.071
Functional Status	.105**	.049	-.093	.083
Coping	-.062	.038	-.068	.089
Problem Stress	.381***	.063	.260	.151
<hr/>				
F=12.93	***p<.001, **p<.01		N=518	

was not included in these analyses; the relationship between social support and coping and their possible joint effects on psychological adjustment will be discussed in a later section.

Tables 6.17 and 6.18 present the results of these regression analyses. As can be seen coping is not significantly associated with general distress and only a weak association with depression is found. Several of the control variables show stronger associations with psychological distress than does coping. Problem stress is clearly the strongest predictor of both depression and general distress. A comparison of the R^2 of these regressions with the regressions of psychological distress only on coping and the control variables shows that inclusion of problem stress in the equation contributes an additional 5 percent to the explained variance. The coping x problem stress interaction term was not significant in either equation. The absence of a significant interaction term indicates that both coping and problem stress have independent effects on psychological distress, although no significant association between coping and general distress was observed.

6.5.3. Summary. This series of analyses has shown only a weak association between coping and psychological distress. This relationship was found to vary somewhat across problem categories, but the associations were only moderate, and no distinct pattern of associations could be

observed. Problem stress showed a significant relationship with psychological distress but no evidence for an interactive effect between coping and problem stress was found.

In considering why a stronger, more consistent relationship between coping and psychological distress was not found two explanations seem important. First, it may be that coping strategies simply are not associated with psychological distress among the disabled. A second explanation may be that the coping index used here does not adequately assess respondents' coping repertoires. Although the majority of items within the coping index were derived from previously published coping scales it is possible that the items selected for use here do not cover a sufficiently diverse range of coping strategies. Alternately it may be that these items are not as relevant for a disabled population. These individuals can be seen as experiencing chronic strains, by virtue of their disability, and they may have developed specific coping strategies for dealing with their problems that are not reflected in the coping items used here. The nature of those strategies would need to be assessed in future research.

6.6. The Relationship Between Self-Esteem and Social Support

Self-esteem has been referred to as an important component of "positive mental health" (Jahoda, 1958). As the literature review in Chapter 2 illustrated, low levels of self-esteem among the physically disabled have frequently been observed. In attempting to understand the association between social support and self-esteem among the disabled several theoretically and empirically relevant variables are included in analyses. Pearlin et al. (1981:345) have stated that "It is the abiding problems to which people can see no end, those that seem to become fixtures of their existence, that are intrinsically uncongenial with positive self-concept." The presence of a physically disabling condition can be seen as a problem that becomes a fixture of one's existence and the disabled may be seen as experiencing chronic strain by virtue of being disabled. To assess how the chronic strain of being disabled may be associated with self-esteem the three disability related variables of duration of disability, functional status and perceived severity are incorporated into analyses.

Life stress is also included in certain analyses. Previous research has suggested that the recent experience of life events has a negative impact on self-esteem (Pearlin et al., 1981; Kaplan, 1970). Pearlin et al. (1981) reported that life events may exacerbate chronic strains, and through their effect on chronic strains they

Table 6.19

ZERO-ORDER CORRELATIONS BETWEEN
SELF-ESTEEM AND SELECTED VARIABLES

	Self-Esteem
Social Support	.32***
Age	-.03
Sex	-.008
Perceived Severity	-.17***
Duration	.06*
Functional Status	.21***
Stress	-.12***
General Distress	-.46***

*** $p \leq .001$, * $p \leq .05$

may enhance vulnerability to loss of self-esteem. In the model of Pearlin et al. (1981) social support is seen as a mediator between life stress, chronic strains and loss of self-esteem. While the direction of causality among these variables cannot be examined within this set of cross-sectional data, inclusion of life stress, together with the disability related variables, will further understanding of the social support/self-esteem relationship among the disabled.

Zero-order correlations between self-esteem and selected variables are presented in Table 6.19. The general distress measure shows the strongest correlation with self-esteem. A moderate association with social support is observed, with higher levels of support associated with higher self-esteem. Stress shows a weak but significant relationship, with higher levels of stress associated with lower self-esteem. Better functional status and a longer disability duration are each significantly associated with higher self-esteem while a perception of one's disability as more severe is significantly related to lower self-esteem. Age and sex are not significantly related to self-esteem.

To examine further the relationship between social support and self-esteem multiple regression analysis was performed. The results are shown in Table 6.20. All variables with the exception of sex and age are significantly related to self-esteem. Social support is the strongest

Table 6.20

Multiple Regression Analysis of Self-Esteem on
Social Support and Control Variables

Variables	Unstandardized Regression Coefficient	Standard Error	Standardized Coefficient	R ²
Perceived Severity	-.567***	.168	-.121	.023
Duration	.025*	.011	.078	.030
Sex	-.215	.307	-.024	.031
Age	-.003	.009	-.010	.031
Functional Status	.283***	.075	.136	.051
Social Support	.855***	.086	.335	.154
<hr/>				
F=23.89	***p<.001, *p<.05		N=738	

predictor of self-esteem and when the effects of the other variables in the equation are controlled social support contributes 10 percent to the explained variance. While the three disability related variables show significant associations with self-esteem they are substantially less powerful predictors. Given the evidence of lower levels of self-esteem among the disabled the disability related variables might have been expected to contribute more to the explained variance in self-esteem. If the disability related variables are viewed as measures of chronic strain, then it appears that chronic strain is not a strong predictor of self-esteem among the disabled. However, it may be that while these measures assess what are presumably important aspects of the disability experience, they do not adequately reflect the chronic strains of being disabled. Chronic strains of disability perhaps exhibit themselves more strongly in terms of social circumstances such as low incomes and high rates of unemployment.

To examine the joint and independent effects of social support, life stress and the disability related variables on self-esteem a second regression analysis was done. The results are shown in Table 6.21. All variables except age, sex, and duration of disability show significant relationships with self-esteem. Social support is the strongest predictor of self-esteem. Only a weak association between life stress and self-esteem is observed and functional status and perceived severity both show stronger

Table 6.21

Multiple Regression Analysis of Self-Esteem on
Social Support, Stress and Control Variables

Variables	Unstandardized Regression Coefficient	Standard Error	Standardized Coefficient	R ²
Perceived Severity	-.526**	.174	-.111	.026
Duration	.022	.012	.067	.030
Sex	-.137	.317	-.015	.033
Age	-.012	.010	-.043	.033
Functional Status	.259***	.077	.125	.051
Social Support	.811***	.089	.316	.158
Stress	-.071**	.027	-.098	.166

F=19.88

***p≤.001, **p≤.01

N=706

relationships with self-esteem than does life stress. The addition of life stress to the regression equation has not contributed to an increase in the explained variance in self-esteem ($R^2=.166$) as compared with the variance explained when stress was not included in the regression equation ($R^2=.164$). These analyses indicate that while chronic strains, assessed in terms of disability related factors, and life stress are significantly associated with self-esteem among the disabled, the relationships are not substantial, and together with social support these variables still account for only a small percentage of the variance explained. The same set of independent variables explained substantially more of the variance in both depression (30%) and general distress (27%).

Adjustments to the standard error of both social support and stress were made in order to take the design effect factor into account. Tests of significance on the newly derived F-statistics showed that social support remained statistically significant at $p \leq .001$ and stress was significant at $p \leq .01$.

To assess further the relationship between social support and self-esteem this regression analysis was repeated with the addition of general distress as an independent variable. Some research has shown a significant association between self-esteem and psychological distress (c.f., Kaplan and Pokorny, 1969; Rosenberg, 1965). While the causal direction of this association

Table 6.22

Multiple Regression Analysis of Self-Esteem on
Social Support, Stress, General Distress
and Control Variables

Variables	Unstandardized Regression Coefficient	Standard Error	Standardized Coefficient	R ²
Age	-.023*	.010	-.084	.0005
Sex	.219	.298	.024	.002
Perceived Severity	-.305	.164	-.065	.028
Duration	.014	.011	.041	.033
Functional Status	.217**	.073	.104	.051
General Distress	-.693***	.068	-.383	.239
Social Support	.509***	.088	.199	.273
Stress	.003	.026	.005	.273
F=32.77 ***p≤.001, **p≤.01, *p≤.05 N=706				

cannot be established within this set of cross-sectional data, it seems appropriate to include general distress in this analysis. Earlier analyses have indicated a significant and substantial association between general distress and both social support and stress. Inclusion of general distress in the regression analysis allows for the observation of the relationship between self-esteem and social support and stress, when the effects of general distress are controlled. The results of this analysis are shown in Table 6.22. Perceived severity, sex, duration and stress fail to attain significance. Consistent with the zero-order correlations, general distress shows the strongest association with self-esteem (standardized coefficient = $-.383$). As can be seen, the association between social support and self-esteem (standardized coefficient = $.199$) is not substantial when the effects of general distress, functional status and age are controlled. The strong association between social support and general distress that was observed in earlier analyses may account, in part, for the weak association between social support and self-esteem when general distress is in the equation. Similarly the significant association between stress and self-esteem that was found in the earlier analysis is not observed when the effects of general distress are controlled. It may be that stress and general distress share the variance that is important for self-esteem and once this variance is accounted for within general distress,

stress is not significant. Alternately it may be that once general distress is in the equation stress is of little importance as stress may be associated with self-esteem primarily through its association with general distress.

In summary, this series of analyses has shown a significant but moderate association between social support and self-esteem. General distress was found to be the strongest predictor of self-esteem, and when the effects of general distress are controlled the association between social support and self-esteem is substantially reduced, and life stress shows no significant relationship with self-esteem. The independent variables considered here explain considerably less of the variance in self-esteem than in either depression or general distress.

6.7. The Relationship Between Self-Esteem and Coping

Table 6.23 presents zero-order correlations between self-esteem and the coping dimensions. Low but significant associations are found between self-esteem and the minimization and emotional support subdimensions, and with the coping summary measure. As only two of the four coping subdimensions show significant relationships, only the coping summary measure will be employed in subsequent analyses. Multiple regression analysis was performed to examine further the association between coping and self-esteem. The results are shown in Table 6.24. All variables except age and sex show significant relationships

Table 6.23

ZERO-ORDER CORRELATIONS BETWEEN
SELF-ESTEEM AND COPING

	Minimization	Emotional Support	Problem Focused	Positive Comparisons	Coping Summary
Self-Esteem	-.18***	-.19***	-.02	-.01	-.20***

*** $p \leq .001$

Table 6.24

Multiple Regression Analysis of
Self-Esteem on Coping and Control Variables

Variables	Unstandardized Regression Coefficient	Standard Error	Standardized Coefficient	R ²
Age	-.003	-.012	-.009	.002
Sex	-.229	.393	-.024	.002
Perceived Severity	-.439*	.213	-.090	.025
Duration	.032*	.015	.090	.037
Functional Status	.376***	.092	.179	.065
Coping	.321***	.072	.187	.099
<hr/> F= 9.73 ***p<.001, *p<.05 N=538				

with self-esteem. A significant association between coping and self-esteem is observed, but the association is not strong. Functional status shows an equally strong association with self-esteem. Together these independent variables explain less than 10 percent of the variance in self-esteem. Thus coping does not appear to be of substantial importance for self-esteem among this sample of disabled adults.

The effect of stratified multi-stage cluster sampling was also considered in assessing the relationship between self-esteem and coping, and after the standard error of coping was adjusted, a statistically significant ($p \leq .001$) association between these variables was still observed.

6.7.1. Variations Across Problem Categories. Zero-order correlations between self-esteem and coping within problem categories are presented in Table 6.25. A significant association between coping and self-esteem is observed in the work, health, daily living and self-care activities categories, with the correlations ranging from low to moderate. These significant correlations are, however, stronger than the correlation observed between self-esteem and coping when type of problem was not taken into consideration, indicating that the association between self-esteem and coping is influenced, at least to some extent, by the nature of the problem.

Previous research has suggested that one of the major goals of coping with illness and disability is to maintain

Table 6.25

ZERO-ORDER CORRELATIONS BETWEEN SELF-ESTEEM AND COPING WITHIN PROBLEM CATEGORIES

Work	Finances	Family	Social Problems	Health	Daily Living	Self Care
.27** (101)	.01 (59)	.03 (85)	.15 (34)	.21** (140)	.38*** (82)	.35* (36)

*** $p \leq .001$, ** $p \leq .01$, * $p \leq .05$

N sizes in brackets

a satisfactory level of self-esteem (c.f., Cohen and Lazarus, 1979; Lipowski, 1970; Moos and Tsu, 1977). Our data suggest that, among the disabled, coping is more strongly associated with self-esteem when the problems are centered most directly on the disability, as evidenced by the significant correlations within the health, daily living and self-care activities categories. In attempting to understand why a stronger association between coping and self-esteem was not observed consistently across problem categories, it can again be suggested that the heterogeneity of the problem categories may obscure some portion of the relationships.

A comparison of these correlations with the correlations between psychological distress and coping (Table 6.16) shows that in the health and work categories a significant association was found only with self-esteem, and in the social problems category a significant relationship was found only with the psychological distress measures. Coping was associated with both self-esteem and psychological distress in the daily living and self-care activities categories. Thus there are both similarities and differences in the relationships between coping and self-esteem and coping and psychological distress, when type of problem is taken into account. It is unclear however, why there is a different pattern in the relationship between coping and the two dimensions of psychological adjustment across problem categories.

Table 6.26

Multiple Regression Analysis of
Self-Esteem on Coping, Problem Stress
and Control Variables

Variables	Unstandardized Regression Coefficient	Standard Error	Standardized Coefficient	R ²
Age	-.004	.012	-.014	.002
Sex	-.184	.397	-.020	.002
Perceived Severity	-.407*	.216	-.083	.025
Duration	.031*	.015	.088	.037
Functional Status	.369***	.093	.176	.065
Coping	.318***	.072	.185	.099
Problem Stress	-.093	.118	-.034	.100
<hr/>				
F=8.427	***p<.001, *p<.05		N=538	

6.7.2. The Role of Problem Stress. Multiple

regression analysis was employed to evaluate the role of problem stress in the relationship between coping and self-esteem. Table 6.26 presents the results of this analysis. Coping shows a weak but significant relationship with self-esteem but no significant association between problem stress and self-esteem is found. The coping x problem stress interaction term was not statistically significant. These results suggest that coping has a direct, although small effect on self-esteem, and this is independent of the effects of problem stress, which shows no direct relationship with self-esteem, and no interactive effect with coping.

These results are considerably different from the regressions of depression and general distress on the same set of independent variables (see Tables 6.17 and 6.18). While coping shows a stronger association with self-esteem than with either psychological distress measure, problem stress was the strongest predictor of both psychological distress measures. Overall these independent variables explain less of the variance in self-esteem ($R^2=.100$) than in depression ($R^2=.169$) or in general distress ($R^2=.151$).

6.7.3. Summary. Coping was shown to be significantly associated with self-esteem among this sample of disabled adults but the association was only moderate. This relationship was found to vary across type of problem,

but the pattern of association did not provide for a substantially clearer understanding of the relationship between coping and self-esteem. Problem stress was not significantly associated with self-esteem and no interactive effect between coping and problem stress was observed.

As with the relationship between coping and psychological distress, the failure to observe a stronger association between coping and self-esteem may be due to inadequacies in the measurement of coping strategies.

6.8. The Relationship Between Social Support and Coping and Their Joint Association with Psychological Distress

Thus far it has been shown that social support is strongly associated with both depression and general distress, and a moderate association with self-esteem was observed. Coping was found to be significantly associated with depression and self-esteem, but a significant relationship with general distress was not observed. In this section the relationship between coping and social support is examined and their joint effects on psychological distress and self-esteem are considered.

The zero-order correlation between the coping summary measure and the summary measure of social support is .25, indicating only a modest association. To examine the joint effects of social support and coping on psychological distress, multiple regression analyses were carried out.

Table 6.27

Multiple Regression Analysis of the CES-D Scale
on Social Support, Coping and Control Variables

Variables	Unstandardized Regression Coefficient	Standard Error	Standardized Coefficient	R ²
Age	-.288	.030	-.040	.0007
Sex	4.363***	.977	.179	.032
Perceived Severity	-2.054***	.535	.162	.069
Duration	-.112**	.038	-.124	.086
Functional Status	.676**	.233	.124	.104
Social Support	-2.789***	.263	-.423	.283
Coping	.000	.000	.000	.283

F=29.51

***p \leq .001, **p \leq .01

N=456

residence would bear importantly on the relationships investigated in this study. As rural residents are likely to reside farther from treatment centers and have more difficulty in receiving medical care and other rehabilitation services, there may be differences in the social support/psychological adjustment relationship. To examine this possibility, multiple regression analyses were done with depression, general distress and self-esteem. A dummy variable was created from urban/rural residence. Social support and the five control variables were forced into the equations first, and the dummy variable and interaction terms between the dummy and other independent variables were then entered. In no instance were any of the interaction terms statistically significant. These analyses suggest there are no significant urban/rural differences in the social support/psychological adjustment relationship. Results of these analyses are presented in Tables 16 through 18 in Appendix C.

Table 6.29

Multiple Regression Analysis of Self-Esteem on
Social Support, Coping and Control Variables

Variables	Unstandardized Regression Coefficient	Standard Error	Standardized Coefficient	R ²
Age	-.004	.012	-.015	.0002
Sex	-.195	.407	-.021	.0004
Perceived Severity	-.441*	.222	-.089	.018
Duration	.038*	.015	.107	.032
Functional Status	.316***	.097	.145	.055
Social Support	.852***	.113	.332	.182
Coping	.162*	.079	.092	.189

F=14.95

***p<.001, **p<.05

N=456

Depression and general distress were each regressed on social support, coping, a support x coping interaction term, and the control variables. A significant support x coping interaction term may suggest that the relationship between social support and psychological distress is influenced by one's coping strategies. A non-significant interaction term may indicate that the effects of social support and coping do not condition each other. Tables 6.27 and 6.28 present the main effects from these analyses. Social support shows the strongest association with both depression and general distress. No significant association between coping and depression, or coping and general distress was observed. The support x coping interaction term was not statistically significant in either equation.

Similar results are observed when self-esteem is regressed on the same set of independent variables. As can be seen from the main effects reported in Table 6.29 social support is the strongest predictor of self-esteem, and a weak but significant association with coping is observed. The coping x support interaction term was not significant at $p \leq .05$.

These analyses indicate that social support has a substantially more powerful association with both psychological distress and self-esteem than does coping. There is no evidence that social support and coping show an interactive effect in their association with these measures of psychological adjustment.

Conclusions about the relationship between social support and coping, based on these findings, must be made cautiously. While it may be that coping is a less powerful predictor of self-esteem and psychological distress, in comparison with social support, the potential inadequacies of the coping measure that were discussed earlier must be taken into consideration. Given the absence of a strong association between coping and psychological adjustment, and the moderate relationship between social support and psychological adjustment that was found in earlier analyses, the results of these analyses are not unexpected. Future studies that employ a more powerful measure of coping strategies will be able to examine the association between coping and social support, and their joint effects on psychological distress and self-esteem more adequately.

6.9. Rural/Urban Differences

As stated earlier, sample selection for this study was designed to allow for a sufficient number of rural residents so that analyses could be conducted separately for urban and rural residents. In the final sample 385 of the respondents were rural residents and 604 were urban residents. While urban/rural differences in the relationships examined here are not a focus of this dissertation some analyses concerning this dimension were done. Urban/rural differences are a theoretically and practically interesting area and it might be expected that place of

residence would bear importantly on the relationships investigated in this study. As rural residents are likely to reside farther from treatment centers and have more difficulty in receiving medical care and other rehabilitation services, there may be differences in the social support/psychological adjustment relationship. To examine this possibility, multiple regression analyses were done with depression, general distress and self-esteem. A dummy variable was created from urban/rural residence. Social support and the five control variables were forced into the equations first, and the dummy variable and interaction terms between the dummy and other independent variables were then entered. In no instance were any of the interaction terms statistically significant. These analyses suggest there are no significant urban/rural differences in the social support/psychological adjustment relationship. Results of these analyses are presented in Tables 16 through 18 in Appendix C.

CHAPTER 7

DISCUSSION AND SUMMARY

7.1. Introduction

Psychological adjustment is considered to be a critical component of overall adaptation among the physically disabled. Research has consistently shown elevated rates of psychological distress among the disabled yet factors that influence variations in psychological adjustment among the disabled have not been firmly established. This study examined the influence of two factors - social support and coping strategies - on psychological adjustment among the disabled.

Respondents for the study were obtained through a stratified multi-stage clustering technique. Screening interviews were conducted at more than 10,000 households in Southwestern Ontario, and from the screenings 1509 persons with physical disabilities were identified. Nine hundred ninety five of these persons participated in this study. The respondents had a wide array of disabilities, with varying degrees of impairment. They ranged in age from 18 - 92 years.

Criteria for inclusion in the study included: 1) a disability duration of three months or longer or an anticipation that the disability would be of long term or permanent duration; 2) aged 18 years or over; 3) no mental

handicaps; 4) community residence, as opposed to residence in institutions for the disabled or aged; 5) ability of the respondent to complete the interview himself - thus persons with insufficient English language abilities and those with severe speech disorders were excluded.

Disability was defined in terms of a limitation in one or more role areas because of a physical health condition. Respondents selected themselves into the study on the basis of their response to a question inquiring about limitations in activities because of physical health problems. While this method of sample recruitment does allow for selection into the study of non-disabled respondents, it also incorporates a mechanism for excluding non-disabled persons. This so because after a respondent has identified himself as disabled in the screening interview, he completes the detailed interview for the disabled, and at that time his disability status can be reviewed. In this study there is little indication that any significant percentage of respondents who had identified themselves as disabled were in fact not disabled. A majority (64%) of respondents indicated that they were very much limited in their activities because of their disabilities and only 6 percent felt their activities were not limited very much. Over 50 percent of respondents perceived their disabling conditions as very severe or severe, and another third considered their disabilities to be somewhat severe. Only 11 percent of respondents rated their disabilities as not very or not

at all severe. Respondents' disabilities were generally of long term duration, with a mean of 13.67 years.

7.2. Social Support and Psychological Adjustment

The first research question of this dissertation dealt with the relationship between social support and psychological adjustment among the disabled. Two measures of social support were employed: The Revised Kaplan Scale and the PSR Scale. Each scale was shown to have satisfactory internal consistency. Analyses indicated that while the two scales were highly correlated there was unique variance in each scale that was importantly associated with psychological distress. Because it therefore seemed important to include both scales in data analyses, these scales were combined to form a summary measure of social support and this summary measure was used in the majority of analyses.

Two dimensions of psychological adjustment were assessed in this study: psychological distress and self-esteem. Self-esteem was measured by a 7-item scale that has shown satisfactory internal consistency, both in this study and elsewhere (Petersen and Kellam, 1975). Some evidence for the validity of this scale has also been produced (Petersen and Kellam, 1975). Psychological distress was evaluated in terms of two dimensions - depression and general distress. Depression was measured by the CES-D Scale, which has been shown to be a reliable instrument for

assessing depressive symptomatology in community samples (Radloff, 1977). The general distress measure evaluated depression and two more general components of distress - anxiety and feelings of anger/aggression. The scales for measuring anxiety and anger/aggression demonstrated satisfactory reliability here and elsewhere (Petersen and Kellam, 1975) and some evidence for their validity is also available (Petersen and Kellam, 1975).

To examine the relationship between social support and psychological adjustment a series of multiple regression analyses were performed. Of the variables considered in the analyses, social support was found to be the strongest predictor of psychological adjustment. Social support was associated somewhat more strongly with depression than with either general distress or self-esteem. The disability related variables made a minimal contribution to the level of psychological adjustment among these disabled subjects. The effects of social support remained significant and substantial when sex, age, duration and perceived severity of the disability, and functional status were controlled.

Life events stress was also included in certain analyses in order to address the question of whether social support is associated directly with psychological distress or acts largely as a buffer of the effects of life stress. Among the total sample and when men and women were considered separately, analyses suggested that social support

has direct effects on psychological distress. No evidence for an interactive effect between support and stress was observed.

The relatively large number of regression analyses on the relationship between social support and psychological adjustment that were performed may raise concerns about the problem of multiple comparisons, whereby some significant relationships are likely to occur simply due to chance. However the consistent pattern of associations that was observed argues against simply random findings of significant associations. In all regressions social support was the strongest predictor of the dependent variables, and was always significant at $p \leq .001$. Further support for the view that the significant findings did not occur by chance alone comes from the "Bonferroni Inequality." Eighteen multiple regressions employed social support as a predictor of psychological adjustment. Multiplying the number of regressions by the P value ($18 \times .001$), a value of $P = .018$ is obtained. This value is still statistically significant at $P \leq .05$.

When social support, stress and the control variables were entered in the regression equation, they explained 30 percent of the variance in depression and 27 percent of the variance in general distress. In each case the cumulative R^2 was statistically significant. However statistical significance does not denote substantive importance and a substantial proportion of the variance in psychological

adjustment is not explained by these independent variables. Nonetheless, it is thought that the percentage of variance explained by these variables is of substantive importance. Given the wide array of factors that are likely to be associated with psychological adjustment, the identification of a small number of variables that explain over 25 percent of the variance in adjustment is of some importance.

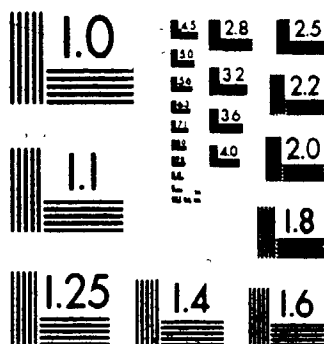
While a large R^2 is always desirable, it should be kept in mind that the intention here was to assess the relationship between social support and psychological adjustment and not to predict as much of the variance in adjustment as possible. Many other variables could have been included in analyses had the purpose been to explain the greatest possible amount of the variance. Lin et al. (1979a) found that 21 percent of the variance in psychiatric symptoms among a sample of Chinese Americans was explained by measures of social support, stress, marital status and occupational prestige and Turner (1981) reported that measures of social support and stress explained 24 percent of the variance in psychological well-being among a group of new mothers. Dean et al. (1980) examined the influence of social support, stress, physical health status and several demographic variables on depression. The proportion of the variance accounted for by these variables differed across age groups, with 44 percent of the variance in depression explained among persons 17-24 years and 26

percent of the variance in depression explained among persons 65 and older. Thus, although the independent variables examined in this study have not explained a substantial amount of the variance in psychological distress the percentage of the variance accounted for is generally comparable with the findings of other studies.

Social support and the control variables account for 16 percent of the explained variance in self-esteem. In a study by Davidson et al. (1981) it was found that social support accounted for 6 percent of the explained variance in self-esteem among moderately burned patients, 14 percent among severely burned patients and 25 percent among critically burned patients. Given the wide range of disability types and severity levels in the present study, it is suggested that these results are roughly comparable with those of Davidson et al. (1981). It can also be noted that, in the present study, when social support alone is considered, it accounts for generally similar amounts of the variance in each of the three measures of psychological adjustment: 15 percent in depression, 12 percent in general distress, and 10 percent in self-esteem.

The consistent association between social support and psychological adjustment among the disabled that was observed in this study suggests that further research in this area may have significant consequences for understanding psychological adjustment among the disabled. It appears that the elevated rates of psychological

3



maladjustment that have been found among the disabled are not strongly related to aspects of the disability itself, such as functional status or duration. Rather, it appears that the social environment is of greater importance for psychological adjustment among the disabled. While this study has shown a significant association between social support and psychological adjustment, the cross-sectional nature of the study does not permit causal inferences and longitudinal studies are needed to examine the causal direction of this relationship.

The finding of an important relationship between social support and psychological adjustment has potential significance for intervention programs aimed at enhancing psychological adjustment among the disabled. If it is assumed that some part of the association between social support and psychological adjustment is a causal effect of social support on adjustment then the finding that social support appears to be more strongly associated with psychological adjustment than are disability related variables can be viewed as a positive factor, in terms of intervention, as social support may be more malleable than aspects of the disability itself. It may be possible to alter social environments such that family and friends become more supportive and the disabled individual perceives himself/herself as the recipient of strong support.

The assumption of a causal association would suggest

that to further understand the relationship between social support and psychological adjustment, and for the design of effective intervention programs, future research should focus on the determinants of support among the disabled. If, as some research has indirectly suggested, the circumstance of being disabled places the availability of support in jeopardy, then a clear understanding of the determinants of support among the disabled is particularly necessary for understanding variations in support. Research is needed to assess whether particular aspects of disability are especially likely to have adverse consequences for the availability of support. Such knowledge may be of value both in identifying disabled persons who are at especially high risk for psychological distress and in designing effective intervention programs.

7.3. Coping and Psychological Adjustment

The second research question concerned the relationship between coping strategies and psychological adjustment. Coping strategies were assessed through a 16-item scale. The majority of items were taken from previously published coping scales and they were intended to evaluate both cognitive and behavioral modes of coping. The scale was shown to have satisfactory internal consistency. Factor analysis produced four coping subdimensions - minimization, emotional support, positive comparisons and problem focused. Correlational analyses showed only a few

significant associations between these coping subdimensions and the measures of psychological adjustment, and these associations were weak. The coping summary measure appeared to provide the best assessment of coping and it was employed in the majority of analyses. Multiple regression analyses indicated a significant but weak association between coping and depression and self-esteem but no significant association with general distress was observed.

The cumulative R^2 s of the depression and self-esteem regressions were statistically significant, but were of such low magnitude as to indicate no substantively important relationship. Analyses showed some variations in the relationship between coping and psychological adjustment when type of problem was considered, but a clear pattern was not observed. Problem stress was shown to be a substantially more powerful predictor of both depression and general distress than was coping, although problem stress was not significantly associated with self-esteem. No interactive effect between coping and problem stress was observed.

Several possible explanations for the failure to observe a stronger association between coping and psychological adjustment can be examined. As was suggested earlier it may be that the coping index did not adequately assess respondents' coping repertoires. This index is best seen as a preliminary step towards the development of more adequate measures. The measurement and theory of coping

are still in the early stages of development. While several coping indices have been developed (Folkman and Lazarus, 1980; Pearlin and Schooler, 1978) at present there are no instruments that are applicable for assessing coping strategies in diverse situations and that are easily incorporated into survey research.

Further development of the theoretical framework of coping is required. With the notable exception of work by Pearlin and Schooler (1978) and Lazarus and his colleagues (Lazarus and Launier, 1978; Cohen and Lazarus, 1973; Folkman and Lazarus, 1980; Folkman, 1979) much of the research on coping has been done on an ad-hoc basis, making comparisons of coping across studies difficult, and hindering progress in the development of effective measuring instruments.

Another explanation for the absence of a stronger relationship may be that coping strategies in general are not strongly or directly related to psychological adjustment among a disabled population. The relationship between coping and psychological adjustment may be importantly influenced by other factors. While this study considered the role of problem type and problem stress level in the coping/psychological adjustment relationship, perhaps the inclusion of other variables in analyses might have increased understanding of this relationship, and also produced a stronger relationship. Some research has suggested that if a situation is appraised as beyond one's control or

as unresponsive to one's efforts to change it, the choice of coping strategies and psychological response may be affected (c.f., Lazarus and Launier, 1978; Folkman and Lazarus, 1980). Inclusion in this study of a measure of the subject's appraisal of the problem situation might have clarified the relationship between coping and psychological adjustment among the disabled.

Inclusion of a measure of problem outcome such as favorable outcome, unfavorable outcome, or not yet resolved, may also have made a contribution to understanding the relationship between coping and psychological adjustment. Respondents' recollections of what they did to cope with the problem, and the perceived stressfulness of the problem may be influenced by the outcome of the problem. Therefore examination of problem outcome might have aided in understanding the association between coping and psychological adjustment.

In conclusion further understanding of the relationship between coping and psychological adjustment among the disabled requires the development of more adequate coping instruments and an examination of other variables that may bear importantly on this relationship.

7.4. The Relationship Between Social Support and Coping

The third research question of this study concerned the relationship between coping and social support and their joint effects on psychological adjustment. A weak

association between these variables was observed through correlational analysis. Multiple regression analyses were employed to assess their independent and joint effects on psychological adjustment. Social support was a substantially stronger predictor of all measures of psychological adjustment than was coping and no significant interaction effects between coping and social support were observed. In light of the strong association between support and psychological adjustment and the minimal association between coping and psychological adjustment that was observed in earlier analyses, these findings were hardly surprising. The weakness of the coping instrument in analyses appears to preclude a reliable evaluation of the relationship between social support and coping and their joint effects on psychological adjustment.

On an intuitive level it seems probable that there is an interesting relationship between coping and social support, and it is likely that causal effects go from both coping to social support and from social support to coping. The coping strategies used by an individual may influence the level of support that is available. An individual who utilizes effective coping strategies may be best able to mobilize his/her support system in times of need. Similarly an individual who is well supported may have the opportunity for coping options that are not as readily available to those who are lacking in support. Social support may inhibit maladaptive coping and reinforce

3. How much does this condition limit your activities, considering what your activities would be if you did not have the condition?

1. very much
2. somewhat
3. not very much
9. don't know/no response

4. How often does this condition interfere with or limit your usual activities?

1. all the time - GO TO QUESTION 6
2. very often
3. often
4. sometimes
5. not very often
6. rarely
9. don't know/no response

5. When was the last time you were affected by this condition?

1. today
2. during the past week
3. during the past two weeks
4. during the past month
5. more than one month ago
9. no response/don't know

6. When was the last time you saw a physician for this condition?

1. during the past week
2. during the past month
3. within the last six months
4. within the last one year
5. more than one year ago
9. no response/don't know

7. How would you rate the severity of this condition?

1. very severe
2. severe
3. somewhat severe
4. not very severe
5. not at all severe
9. no response/don't know

substantial impact on the generalizability of the study findings.

The sampling procedures employed in this study also raise some issues concerning generalizability. In order to obtain a sufficient number of rural disabled, rural/urban residents were sampled in a 2:1 ratio. Thus rural disabled are overrepresented in this sample, relative to their actual proportion in the population. However in terms of generalizing the results of this study to disabled residents of Southwestern Ontario, this oversampling does not restrict generalizability, as this study has focused on associations between variables, and as has been shown, these associations do not differ significantly between urban and rural residents.

In summary, the results of this study are likely to be generalizable to disabled adults living in the community, in both urban and rural areas, in Southwestern Ontario. However some caution in generalizing the study findings to disabled individuals over age 64 is warranted.

APPENDIX A

QUESTIONNAIRES

PLEASE NOTE: Separate forms were used for male and female participants. The difference occurs only in Section 13 of the questionnaire, where male or female names were used. The appended questionnaire is the version for males.

SUBJECT I. D. NUMBER	_____
HOUSEHOLD I. D. NUMBER	_____
COUNTY	_____
F. E. D.	_____
E. A.	_____
AREA	_____
FORM 2	

STUDY OF PHYSICAL HEALTH PROBLEMS

FULL INTERVIEW

Respondent's Name: _____

Address: _____

Telephone: _____

Date: _____

Consent Signed: Yes _____

No _____

STUDY OF PHYSICAL HEALTH PROBLEMS

SUBJECT I. D. NUMBER _____

COUNTY _____

F. E. D. _____

E. A. _____

AREA _____

FORM 2

My name is _____. I represent the Health Care Research Unit at the University of Western Ontario. (As you recall from the letter we left with you) we are conducting a health survey in this area, and your house was selected to be part of this survey by a random sampling procedure. The major focus of the survey is on physical conditions or problems that in some way limit an individual's functioning. We are interested in learning something about your health condition, the way it affects your life, and the ways in which you cope with it. Your responses to the questions will be kept completely confidential, using an identification-numbering system and a locked filing cabinet to ensure that no unauthorized person has access to the information. You are free to refuse to answer any questions and you are free to terminate the interview at any time.

SECTION 1: HEALTH CONDITION

First, I'd like to ask you a few questions about the health problems you have that limit or interfere with your activities.

1. What physical problem would you say is the main cause of your limitation? I'd like you to think about this and name only the most important cause. If you have more than one limiting health condition we can talk about the others shortly.

PROBE: IF SYMPTOM IS GIVEN ASK FOR CAUSE OF SYMPTOM
GET MEDICAL TERM IF POSSIBLE

2. How old were you when this first occurred?

_____ years old

9. don't know/no response

3. How much does this condition limit your activities, considering what your activities would be if you did not have the condition?

1. very much
2. somewhat
3. not very much
9. don't know/no response

4. How often does this condition interfere with or limit your usual activities?

1. all the time - GO TO QUESTION 6
2. very often
3. often
4. sometimes
5. not very often
6. rarely
9. don't know/no response

5. When was the last time you were affected by this condition?

1. today
2. during the past week
3. during the past two weeks
4. during the past month
5. more than one month ago
9. no response/don't know

6. When was the last time you saw a physician for this condition?

1. during the past week
2. during the past month
3. within the last six months
4. within the last one year
5. more than one year ago
9. no response/don't know

7. How would you rate the severity of this condition?

1. very severe
2. severe
3. somewhat severe
4. not very severe
5. not at all severe
9. no response/don't know

8. Now I would like to know if you have any other conditions, in addition to the main condition, that limit or interfere with your activities?

1. yes
2. no - GO TO QUESTION 9
9. no response/don't know - GO TO QUESTION 9

FOR EACH CONDITION LISTED, ASK AGE AT ONSET, HOW MUCH THIS CONDITION LIMITS ACTIVITIES, HOW OFTEN THE INDIVIDUAL IS AFFECTED BY THIS CONDITION, LAST TIME AFFECTED BY THIS CONDITION, AND SEVERITY OF CONDITION. USE THE FOLLOWING CODES AND WRITE NUMBERS IN CHART BELOW.

HOW MUCH ACTIVITIES AFFECTED:

1. very much?
2. somewhat?
3. not very much?
9. no response/don't know

HOW OFTEN AFFECTED:

1. all the time?
2. very often?
3. often?
4. sometimes?
5. not very often?
6. rarely?
9. no response/don't know

LAST TIME AFFECTED:

1. today?
2. during the past week?
3. during the past two weeks?
4. during the past month?
5. more than one month ago?
9. no response/don't know

SEVERITY:

1. very severe?
2. severe?
3. somewhat severe?
4. not very severe?
5. not at all severe?
9. no response/don't know

Condition	Age at Onset	How Much	How Often	Last Time	Severity

9. In the past four months has your limiting health condition changed in any way?

Has it been:

1. better?
2. worse?
3. no change? - GO TO QUESTION 11
9. no response/don't know - GO TO QUESTION 11

10. How much has your limiting health condition changed in the last four months?
Would you say:

1. very much?
2. moderately?
3. not very much?
9. no response/don't know

11. Sometimes, even though the actual physical condition doesn't change, the limitations associated with the condition - that is, things you can or cannot do - may change. In your case, whether or not the underlying physical condition has changed over the past four months, have the resulting limitations changed?

1. yes
2. no - GO TO QUESTION 14
9. no response/don't know - GO TO QUESTION 14

12. Would you say that the change in your limitations has been for the better or worse?

1. better
2. worse
9. no response/don't know

13. Over the past four months, how much have your limitations changed?
Would you say:

1. very much?
2. moderately?
3. not very much?
9. no response/don't know

14. In the past month, how often have any of your health conditions caused you pain?

1. every day
2. 2 - 3 days a week
3. at least once a week
4. 2 - 3 times in the past month
5. never - GO TO QUESTION 17
9. no response/don't know

15. In general, how would you rate the severity of your pain in the last month?
Would you say it is:

1. unbearable pain?
2. very severe pain?
3. severe pain?
4. moderate pain?
5. mild pain?
9. no response/don't know

16. When the pain is at its worst how much does it restrict the things you can do?

1. very much
2. moderately
3. not very much
4. not at all
9. no response/don't know

SECTION 2. DEMOGRAPHICS

Now I would like to ask you a few questions about yourself.

17. RECORD SEX OF RESPONDENT.

1. male
2. female

18. In what year were you born?

_____ (year of birth)

9. no response/don't know

19. What is your current marital status:

1. single/never married?
2. married?
3. separated?
4. divorced?
5. common-law?
6. widowed?
9. no response

20. At the time you became aware of the health condition we have been discussing, what was your marital status:

1. single/never married?
2. married?
3. separated?
4. divorced?
5. common-law?
6. widowed?
9. no response

IF CHANGE IN STATUS IS BECOMING WIDOWED - GO TO QUESTION 23

ALL OTHER CHANGES IN STATUS - GO TO QUESTION 21

IF NO CHANGE IN STATUS - GO TO QUESTION 23

21. Was this change in marital status related in any way to your health condition?

1. yes
2. no - GO TO QUESTION 23
9. no response/don't know - GO TO QUESTION 23

22. Could you tell me a little about this?

9. no response

23. a) What job did your father do for most of his working life?

9. no response/don't know

b) What kind of work did it involve?

9. no response/don't know

SECTION 3: RESIDENCE

Now I am going to ask you a few questions about the place you live in.

24. CODE TYPE OF RESIDENCE.

1. house
2. apartment
3. boarding house/room
4. retirement community or apartment
5. other (SPECIFY) _____

25. CODE TYPE OF COMMUNITY.

1. farm
2. rural non-farm (less than 1,000 population)
3. town (1,000 to 9,999 population)
4. small city (10,000 to 99,999 population)
5. large urban area (100,000 plus population)
6. other (SPECIFY) _____

26. How many people live in this house, not counting yourself?

9. no response/don't know

27. How long have you lived in this residence?

9. no response/don't know

28. Have you ever changed residence because of your physical health limitations?

- 1. yes
- 2. no
- 9. no response/don't know

IF YES: Could you tell me a bit about how your moving was related to your health?

9. no response/don't know

29. Are there any rooms inside your home that you cannot use or have difficulty in using because of your limiting health condition?

- 1. yes
- 2. no
- 9. no response/don't know

IF YES: About how many rooms do you have difficulty in using? Would you say with :

- 1. less than half the rooms in your house?
- 2. about half the rooms in your house?
- 3. most or all of the rooms in your house?
- 9. no response/don't know

30. Do you have any difficulty in getting inside and outside of your home?

1. yes
2. no
9. no response/don't know

31. Often, in the light of physical limitations, some people need to make adaptations or modifications to their place of residence. Have you made any adaptations to your home or are there any adaptations you feel would be beneficial to you?

CIRCLE AS MANY AS APPLY

1. yes, I have made some adaptations - GO TO QUESTION 33
2. yes, there are some adaptations that would be beneficial for me
3. no, I have not made any adaptations - GO TO QUESTION 33
4. no, I do not need any adaptations - GO TO QUESTION 33
9. no response/don't know

32. Could you tell me why you haven't made those adaptations to your residence that you feel would be beneficial to you?

Is it because:

1. it's too expensive?
2. you are renting - not allowed to do?
3. other (SPECIFY) _____
9. no response/don't know

SECTION 4: COPING

33. a) Many people experience problems or worries because of their health conditions. Please think back over the last year and tell me what was the most difficult problem or worry you had because of your health condition. (PROBE FOR FULL RESPONSE - WHAT HAPPENED, WHO WAS INVOLVED, WHAT MADE IT STRESSFUL)

IF RESPONDENT SAYS NONE, EMPHASIZE IT COULD BE ABOUT FAMILY, FRIENDS/SOCIAL ACTIVITIES, HEALTH/FEELINGS ABOUT HEALTH, WORK/FINANCES.

99. no response/don't know - GO TO QUESTION 33b

Now I would like to know how stressful you found this problem. On a scale ranging from 1 to 7, with 7 being very stressful and 1 being mildly stressful, how would you rate the stress of this problem? Please pick the number on this scale that best describes how stressful this was for you.

INTERVIEWER: HAND RESPONDENT WHITE CARD

1	2	3	4	5	6	7
mildly stressful			moderately stressful			very stressful

INTERVIEWER: TAKE BACK WHITE CARD AND GO TO QUESTION 34.

IF RESPONDENT HAS NO HEALTH RELATED PROBLEM:

33. b) How about a problem or worry you have had that was not related to your health problem. Please take a minute to think back over the past year and tell me what was the most difficult problem or worry you had?

PROBE FOR FULL RESPONSE--EMPHASIZE AGAIN IT COULD BE ABOUT FAMILY, FRIENDS/SOCIAL ACTIVITIES, HEALTH, FEELINGS ABOUT HEALTH, WORK/FINANCES.

99. no response/don't know - GO TO QUESTION 35.

Now I would like to know how stressful you found this problem. On a scale ranging from 1 to 7, with 7 being very stressful and 1 being mildly stressful, how would you rate the stress of this problem? Please pick the number on this scale that best describes how stressful this was for you.

INTERVIEWER: HAND RESPONDENT WHITE CARD

1	2	3	4	5	6	7
mildly			moderately			very
stressful			stressful			stressful

INTERVIEWER: TAKE BACK WHITE CARD

34. Did you do any of these things to help yourself deal with this problem?

Did you:	<u>Yes</u>	<u>No</u>	<u>No Response</u> <u>Don't Know</u>
a) bargain or compromise to get something good from the situation?	1	2	9
b) turn to a friend or relative for advice?	1	2	9
c) accept the situation because there was nothing you could do about it?	1	2	9
d) go on as if nothing had happened?	1	2	9
e) keep yourself busy with other things?	1	2	9
f) try not to get too serious about it - laugh it off?	1	2	9
g) remind yourself that things could be a lot worse?	1	2	9
h) do something that you didn't think would help but at least you were doing something?	1	2	9
i) not let on to anyone how bad things were?	1	2	9
j) come up with a couple of different solutions to the problem?	1	2	9
k) get professional help and do what was recommended	1	2	9
l) concentrate on something good that could come out of the whole thing - look for the silver lining?	1	2	9
m) tell yourself things that helped you to feel better?	1	2	9
n) take your problems out on other people?	1	2	9
o) feel that time would make a difference - the only thing to do was wait?	1	2	9
p) make a plan of action and follow it?	1	2	9

	<u>Yes</u>	<u>No</u>	<u>No Response</u> <u>Don't Know</u>
q) try to forget it - put it out of your mind?	1	2	9
r) let your feelings out somehow?	1	2	9
s) sit down and talk things out with the other people involved?	1	2	9
t) remind yourself that you were a lot better off than some people?	1	2	9
u) pray to God	1	2	9

34 a. Did you do anything else to try to deal with the problem?

1. yes
2. no

IF YES, what did you do?

SECTION 5: EDUCATION

Now I would like to ask you some questions about your education and work experience.

35. What is the highest grade you ever completed at school? (CIRCLE)

0 - none

1 2 3 4 5 6 7 8 9 10 11 12 13

99. no response/don't know

36. How many years of schooling have you had since secondary school?

0 - none

University - 1 2 3 4 5 6+

Other (SPECIFY) _____

1 2 3+ years

9. no response/don't know

37. Did your limiting health condition:

1. cause you to leave school earlier than planned?

2. influence your educational plans (SPECIFY-IN WHAT WAY)

3. occur after you completed your education?

4. have no effect on your educational plans or program?

9. no response/don't know

38. As a result of your condition have you taken any special training or education, including job retraining?

1. yes

2. no - GO TO QUESTION 39

9. no response/don't know

IF YES: What was the nature of this training? (SPECIFY) _____

9. no response/don't know

IF YES: Who suggested you take it?

1. self

2. other (PROBE: family, specific agency, doctor)

9. no response/don't know

NOW: GO TO QUESTION 41

39. Could you tell me why you have not taken any special training or educational programs as a result of your condition?

Is it because: CIRCLE AS MANY AS APPLY

1. you have no need for these programs?
2. you have not been aware of the existence of these programs?
3. it is too difficult and/or inconvenient to participate in these programs?
4. you are not interested in taking these programs?
5. other (SPECIFY) _____
9. no response/don't know

40. Has it ever been suggested that you take a specific education or training program because of your health condition?

1. yes
2. no
9. no response/don't know

IF YES: What kind of course was suggested? _____

- _____
9. no response/don't know

IF YES: Who suggested it? (PROBE: family, specific agency, doctor)

- _____
9. no response/don't know

SECTION 6: EMPLOYMENT

41. What is your current employment status?

- | | |
|---------------------------|---------------------|
| 1. employed full time | - GO TO QUESTION 43 |
| 2. employed part time | - GO TO QUESTION 42 |
| 3. unemployed | - GO TO QUESTION 47 |
| 4. student | - GO TO QUESTION 47 |
| 5. retired | - GO TO QUESTION 47 |
| 6. housewife | - GO TO QUESTION 47 |
| 7. sick leave | - GO TO QUESTION 43 |
| 8. other (SPECIFY) _____ | - GO TO QUESTION 47 |
| 9. no response/don't know | - GO TO QUESTION 47 |

FOR PEOPLE EMPLOYED PART TIME:

42. Are you not working full time because:

1. you prefer to work part time?
2. you cannot find full time work?
3. you cannot work full time because of your health?
4. other (SPECIFY) _____
9. no response/don't know

FOR ALL THOSE CURRENTLY EMPLOYED FULL OR PART TIME

43. What is your current job called?

44. What kind of work does it involve?

45. How long have you worked at this job?

_____ months _____ years

9. no response/don't know

46. a) How physically demanding do you think the average person would find your job?

1. not at all physically demanding
2. somewhat physically demanding
3. very physically demanding
9. no response/don't know

b) How physically demanding do you find your job?

1. not at all physically demanding
2. somewhat physically demanding
3. very physically demanding
9. no response/don't know

FOR THOSE NOT CURRENTLY EMPLOYED:

47. Have you ever had paid employment?

1. yes, full time
2. yes, part time
3. no - GO TO QUESTION 68
9. no response/don't know

48. In what year were you last employed?

-
9. no response/don't know

49. What was that job called?

-
9. no response/don't know

50. What kind of work did it involve?

51. How long did you have that job?

_____ months _____ years

9. no response/don't know

52. Did you leave that job for reasons related to your health condition?

1. yes (SPECIFY) _____
2. no
9. no response/don't know

53. Could you tell me why you are not working now? Is it because:

1. it's your personal choice?
2. you can't find a job?
3. you are not able to work because of your health?
4. you are not hired because of your health?
5. you are retired?
6. other (SPECIFY) _____
9. no response/don't know

FOR ALL RESPONDENTS WHO HAVE EVER WORKED, INCLUDING THOSE CURRENTLY EMPLOYED AND THOSE NOT CURRENTLY EMPLOYED.

INTERVIEWER: QUESTIONS 54 TO 62 TO BE ASKED ONLY OF PEOPLE WITH ADULT ONSET OF DISABILITY.

54. I would like to know something about your occupational history.

Before the onset of your physical health problems, what job had you held for the longest period of time?

9. no response/don't know

55. What kind of work did it involve?

9. no response/don't know

56. How long did you work at this job?

_____ months _____ years

9. no response/don't know

57. Have you changed jobs or quit working since the onset of your health problems?

1. yes, I changed jobs
2. yes, I quit working
3. no, I quit working before the onset of my health problems. - GO TO QUESTION 62
4. no, I have the same job as before the onset of my health problems. - GO TO QUESTION 62
9. no response/don't know

58. What job have you held (did you have) for the longest period of time since the onset of your condition?

-
8. none - quit work immediately after onset GO TO QUESTION 61
 9. no response/don't know

59. What type of work did (does) it involve?

-
-
9. no response/don't know

60. How long did you work at this job?

-
- months _____ years _____
9. no response/don't know

61. Did you change jobs or quit working because of your physical health problems?

1. yes (DESCRIBE) _____
2. no _____
9. no response/don't know

62. In the past five years, about how many months have you worked?

-
9. no response/don't know
- GO TO QUESTION 68

INTERVIEWER: QUESTIONS 63 TO 67 TO BE ASKED ONLY OF PERSONS WITH CONGENITAL OR CHILDHOOD ONSET WHO HAVE EVER WORKED.

I would like to know something about your occupational history.

63. What job have you held for the longest period of time?

9. no response/don't know

64. What type of work does (did) it involve?

9. no response/don't know

65. How long did you work at this job?

_____ months _____ years

9. no response/don't know

66. Have you ever had to change jobs because of your physical health?

1. yes (DESCRIBE WHY) _____
2. no
9. no response/don't know

67. In the past five years, about how many months have you worked?

9. no response/don't know

68. Now I would like to ask you a few questions about jobs around the house. For each job I read to you, please use the scale on this card to tell me the number of the category that describes how often you do these jobs in an average week.

1. always or most of the time
2. occasionally or a moderate amount of the time
3. some or a little of the time
4. rarely or none of the time
9. no response/don't know

INTERVIEWER: HAND RESPONDENT PALE BLUE CARD

How often do you:

a) wash dishes after meals	1	2	3	4	9
b) go grocery shopping	1	2	3	4	9
c) do laundry	1	2	3	4	9
d) cook meals	1	2	3	4	9
e) do light cleaning (dusting, sweeping)	1	2	3	4	9
f) do heavy cleaning (wash floors, windows)	1	2	3	4	9

INTERVIEWER: TAKE BACK PALE BLUE CARD

SECTION 7: INCOME AND FINANCES

I'd like to know something about you and your family's financial circumstances. I realize these are extremely personal matters and I wish to assure you again that your responses will be kept strictly confidential.

69. On this card are several categories of income. Would you please read to me the number of the category that gives the best estimate of your personal income before taxes.

INTERVIEWER: HAND RESPONDENT BRIGHT YELLOW CARD

1. under \$5,000.00
2. \$ 5,000.00 to \$ 9,999.00
3. \$10,000.00 to \$14,999.00
4. \$15,000.00 to \$24,999.00
5. \$25,000.00 to \$34,999.00
6. \$35,000.00 to \$44,999.00
7. \$45,000.00 and over
8. refused
9. no response/don't know

70. Now, using the same categories, which one gives the best estimate of your total household income before taxes?

1. under \$5,000.00
2. \$ 5,000.00 to \$ 9,999.00
3. \$10,000.00 to \$14,999.00
4. \$15,000.00 to \$24,999.00
5. \$25,000.00 to \$34,999.00
6. \$35,000.00 to \$44,999.00
7. \$45,000.00 and over
8. refused
9. no response/don't know

INTERVIEWER: TAKE BACK BRIGHT YELLOW CARD

71. Are you now receiving a disability pension or disability/health insurance benefits?

1. yes
2. no
9. no response/don't know

IF YES: What kind of disability pension or insurance benefits are you receiving?

CIRCLE AS MANY AS APPLY

1. Ontario government disability pension
2. Federal government disability pension
3. Workmen's Compensation Board pension
4. private company pension
5. disability/health insurance benefits
6. other _____
9. no response/don't know?

IF NO: Have you ever received a disability pension or disability/health insurance benefits?

1. yes
2. no
9. no response/don't know

IF YES: What kind of disability pension or disability/health insurance benefits did you receive?

CIRCLE AS MANY AS APPLY

1. Ontario government disability pension
2. Federal government disability pension
3. Workmen's Compensation Board pension
4. private company pension
5. disability/health insurance benefits
6. other _____
9. no response/don't know

72. What are the three primary sources of income for your household?

1. salary, wages, fees
2. disability pension, disability insurance benefits, workmen's compensation
3. Canada Pension, Quebec Pension, private retirement pension, veterans pension
4. unemployment insurance
5. welfare
6. bond/deposit interest dividends, other investment income
7. other income (SPECIFY) _____
9. no response/don't know

73. When you think of your financial situation overall, how difficult is it for you to meet the following commitments?

	<u>very</u> <u>difficult</u>	<u>some-</u> <u>what</u> <u>difficult</u>	<u>not at</u> <u>all</u> <u>difficult</u>	<u>no response</u> <u>don't know</u>
a. housing	1	2	3	9
b. food	1	2	3	9
c. personal expenses	1	2	3	9
d. transportation	1	2	3	9
e. medical expenses	1	2	3	9
f. other (SPECIFY) _____	1	2	3	9

SECTION 8: YOUR FEELINGS

The following groups of questions deal with your feelings.

74. I am going to read some statements that describe how people sometimes feel. Please use the scale on this card and tell me the number of the category that best describes how you have been feeling recently.

INTERVIEWER: HAND RESPONDENT BRIGHT PINK CARD

1. not like me at all
2. not much like me
3. somewhat like me
4. much like me
5. very much like me
9. no response/don't know

- | | | | | | | |
|---|---|---|---|---|---|---|
| a) I feel strong and healthy. | 1 | 2 | 3 | 4 | 5 | 9 |
| b) I am easily startled. | 1 | 2 | 3 | 4 | 5 | 9 |
| c) I can change my plans or mind
if I get new information. | 1 | 2 | 3 | 4 | 5 | 9 |
| d) When I get angry, I stay angry. | 1 | 2 | 3 | 4 | 5 | 9 |
| e) I feel tense. | 1 | 2 | 3 | 4 | 5 | 9 |
| f) I yell at people. | 1 | 2 | 3 | 4 | 5 | 9 |
| g) I like being the way I am. | 1 | 2 | 3 | 4 | 5 | 9 |
| h) I feel nervous. | 1 | 2 | 3 | 4 | 5 | 9 |
| i) I'm good at what I do. | 1 | 2 | 3 | 4 | 5 | 9 |
| j) I feel like I am boiling inside. | 1 | 2 | 3 | 4 | 5 | 9 |
| k) When faced with a problem I can work it out. | 1 | 2 | 3 | 4 | 5 | 9 |
| l) My hands sometimes shake. | 1 | 2 | 3 | 4 | 5 | 9 |
| m) I lose my temper. | 1 | 2 | 3 | 4 | 5 | 9 |
| n) When I fail at something I try again. | 1 | 2 | 3 | 4 | 5 | 9 |
| o) I feel tight inside. | 1 | 2 | 3 | 4 | 5 | 9 |
| p) I am a worthwhile person. | 1 | 2 | 3 | 4 | 5 | 9 |
| q) I feel angry. | 1 | 2 | 3 | 4 | 5 | 9 |
| r) New situations make me tense. | 1 | 2 | 3 | 4 | 5 | 9 |
| s) I get into fights or arguments. | 1 | 2 | 3 | 4 | 5 | 9 |
| t) I feel under pressure. | 1 | 2 | 3 | 4 | 5 | 9 |

INTERVIEWER: TAKE BACK BRIGHT PINK CARD

75. We already asked you how you sometimes feel about yourself. Now we are interested in knowing how you feel you are seen by others. Please use the scale on this card and tell me the number of the category that best describes how certain you are.

INTERVIEWER: HAND RESPONDENT DARK BLUE CARD

1. I am very certain this is true.
2. I am somewhat certain this is true.
3. I am uncertain about this.
4. I am somewhat certain this is not true.
5. I am very certain this is not true.
9. no response/don't know

- | | | | | | | |
|---|---|---|---|---|---|---|
| a) Other people think I am comfortable with the way I am. | 1 | 2 | 3 | 4 | 5 | 9 |
| b) Other people think that I am good at what I do. | 1 | 2 | 3 | 4 | 5 | 9 |
| c) Other people think that I can work out problems that face me. | 1 | 2 | 3 | 4 | 5 | 9 |
| d) Other people feel that when I fail at something, I will try again. | 1 | 2 | 3 | 4 | 5 | 9 |
| e) Other people think that I am a worthwhile person. | 1 | 2 | 3 | 4 | 5 | 9 |

INTERVIEWER: TAKE BACK DARK BLUE CARD

28

76. I am going to read some statements that describe how people sometimes feel or behave. Please use the scale on this card to tell me the number of the category that best describes how often you have felt this way during the past week.

1. Rarely or none of the time (less than one day)
2. Some or a little of the time (1 to 2 days)
3. Occasionally or a moderate amount of time (3 to 4 days)
4. Most or all of the time (5 to 7 days)
9. no response/don't know

INTERVIEWER: HAND RESPONDENT WHITE CARD

During the past week:

- | | | | | | |
|--|---|---|---|---|---|
| a) I was bothered by things that usually don't bother me. | 1 | 2 | 3 | 4 | 9 |
| b) I did not feel like eating; my appetite was poor. | 1 | 2 | 3 | 4 | 9 |
| c) I felt that I could not shake off the blues even with help from my family or friends. | 1 | 2 | 3 | 4 | 9 |
| d) I felt that I was just as good as other people. | 1 | 2 | 3 | 4 | 9 |
| e) I had trouble keeping my mind on what I was doing. | 1 | 2 | 3 | 4 | 9 |
| f) I felt depressed. | 1 | 2 | 3 | 4 | 9 |
| g) I felt that everything I did was an effort. | 1 | 2 | 3 | 4 | 9 |
| h) I felt hopeful about the future. | 1 | 2 | 3 | 4 | 9 |
| i) I thought my life had been a failure. | 1 | 2 | 3 | 4 | 9 |
| j) I felt fearful. | 1 | 2 | 3 | 4 | 9 |
| k) My sleep was restless. | 1 | 2 | 3 | 4 | 9 |
| l) I was happy. | 1 | 2 | 3 | 4 | 9 |
| m) I talked less than usual. | 1 | 2 | 3 | 4 | 9 |
| n) I felt lonely. | 1 | 2 | 3 | 4 | 9 |
| o) People were unfriendly. | 1 | 2 | 3 | 4 | 9 |
| p) I enjoyed life. | 1 | 2 | 3 | 4 | 9 |
| q) I had crying spells. | 1 | 2 | 3 | 4 | 9 |
| r) I felt sad. | 1 | 2 | 3 | 4 | 9 |
| s) I felt that people disliked me. | 1 | 2 | 3 | 4 | 9 |
| t) I could not get "going". | 1 | 2 | 3 | 4 | 9 |

INTERVIEWER: TAKE BACK WHITE CARD

77. For each of the following statements I am going to read to you please use the scale on this card to tell me the number of the category that describes how strongly you agree or disagree with each statement.

1. strongly agree
2. mildly agree
3. neither agree nor disagree
4. mildly disagree
5. strongly disagree
9. no response/don't know

INTERVIEWER: HAND RESPONDENT PALE ORANGE CARD

- | | | | | | | |
|--|---|---|---|---|---|---|
| a) I have little control over the things that happen to me. | 1 | 2 | 3 | 4 | 5 | 9 |
| b) There is really no way I can solve some of the problems I have. | 1 | 2 | 3 | 4 | 5 | 9 |
| c) There is little I can do to change many of the important things in my life. | 1 | 2 | 3 | 4 | 5 | 9 |
| d) I often feel helpless in dealing with problems of life. | 1 | 2 | 3 | 4 | 5 | 9 |
| e) Sometimes I feel that I am being pushed around in life. | 1 | 2 | 3 | 4 | 5 | 9 |
| f) What happens to me in the future mostly depends on me. | 1 | 2 | 3 | 4 | 5 | 9 |
| g) I can do just about anything I really set my mind to. | 1 | 2 | 3 | 4 | 5 | 9 |

INTERVIEWER: TAKE BACK PALE ORANGE CARD

SECTION 9: SOCIAL AND RECREATIONAL ACTIVITIES

In this section I would like to ask you some questions on how you spend your leisure time.

78. I am going to read a list of activities that people sometimes do in their spare time. Please use the scale on this card to tell me the number of the category that describes how often you do each of these.

INTERVIEWER: HAND RESPONDENT BRIGHT ORANGE CARD

- | | |
|--------------------------|---------------------------|
| 1. daily | 5. once a month or less |
| 2. more than once a week | 6. never |
| 3. once a week | 9. no response/don't know |
| 4. 2 - 3 times a month | |

ACTIVITY

a) visit friends	1	2	3	4	5	6	9
b) go to beaches, zoos, parks	1	2	3	4	5	6	9
c) watch t.v.	1	2	3	4	5	6	9
d) go to dinner in a restaurant	1	2	3	4	5	6	9
e) go to concerts, plays, museums, movies	1	2	3	4	5	6	9
f) spend time on hobby, painting, music	1	2	3	4	5	6	9
g) read	1	2	3	4	5	6	9
h) go to church or church groups	1	2	3	4	5	6	9
i) go to club meetings (bridge)	1	2	3	4	5	6	9
j) attend educational activities (Fanshawe, P.U.C., Board of Education)	1	2	3	4	5	6	9
k) have friends drop in unexpectedly	1	2	3	4	5	6	9
l) playing cards, other indoor games	1	2	3	4	5	6	9
m) talk to friends and relatives on the phone	1	2	3	4	5	6	9
n) other (SPECIFY) _____	1	2	3	4	5	6	9

INTERVIEWER: TAKE BACK BRIGHT ORANGE CARD

79. How about activities that are more physically demanding than those we just talked about - do you participate in any of these?

1. yes
2. no
9. no response/don't know

IF YES: What activities do you do?

1. _____
2. _____
3. _____
4. _____
9. no response/don't know

80. Thinking about your leisure time activities overall, how much time do you spend doing these activities by yourself:

1. most or all of the time?
2. occasionally or a moderate amount of time?
3. some or a little of the time?
4. rarely or none of the time?
9. no response/don't know

81. Now I would like to know something about your relationships with other people. For each of the statements I read to you please use the scale on this card to tell me the number of the category that best describes your experience.

INTERVIEWER: HAND RESPONDENT GREEN CARD

1. very much like my experience
2. much like my experience
3. somewhat like my experience
4. not very much like my experience
5. not at all like my experience
9. no response/don't know

a) When I'm with my friends
I feel completely able to
relax and be myself.

1 2 3 4 5 9

b) I share the same approach to
life that many of my friends do.

1 2 3 4 5 9

1. very much like my experience
2. much like our my experience
3. somewhat like my experience
4. not very much like my experience
5. not at all like my experience
9. no response/don't know

- | | | | | | | |
|--|---|---|---|---|---|---|
| c) My friends don't know one another well. | 1 | 2 | 3 | 4 | 5 | 9 |
| d) People who know me trust me and respect me. | 1 | 2 | 3 | 4 | 5 | 9 |
| e) No matter what happens, I know that my family will always be there for me should I need them. | 1 | 2 | 3 | 4 | 5 | 9 |
| f) When I want to go out to do things I know that many of my friends would enjoy doing these things with me. | 1 | 2 | 3 | 4 | 5 | 9 |
| g) I have at least one friend that I could tell anything to. | 1 | 2 | 3 | 4 | 5 | 9 |
| h) Sometimes I'm not sure if I can completely rely on my family. | 1 | 2 | 3 | 4 | 5 | 9 |
| i) My friends do not always approve of my attitudes and lifestyle. | 1 | 2 | 3 | 4 | 5 | 9 |
| j) My family lets me know they think I'm a worthwhile person. | 1 | 2 | 3 | 4 | 5 | 9 |
| k) I feel very close to some of my friends. | 1 | 2 | 3 | 4 | 5 | 9 |
| l) People in my family have confidence in me. | 1 | 2 | 3 | 4 | 5 | 9 |
| m) There are some problems that I can't share with anyone. | 1 | 2 | 3 | 4 | 5 | 9 |
| n) People in my family provide me with help in finding solutions to my problems. | 1 | 2 | 3 | 4 | 5 | 9 |
| o) People who know me think I am good at what I do. | 1 | 2 | 3 | 4 | 5 | 9 |
| p) My friends would take the time to talk over my problems, should I ever want to. | 1 | 2 | 3 | 4 | 5 | 9 |
| q) I know my family will always stand by me. | 1 | 2 | 3 | 4 | 5 | 9 |
| r) Even when I am with my friends I feel alone. | 1 | 2 | 3 | 4 | 5 | 9 |

INTERVIEWER: TAKE BACK GREEN CARD

82. We are also interested in knowing if there is a special person in your life in whom you can really trust and confide. Do you have a confidant, that is someone with whom you can really talk about problems or how you are feeling?

1. yes
2. no - GO TO QUESTION 83
9. no response/don't know

(a) Are you and this person the:

1. same sex?
2. opposite sex?
9. no response/don't know

(b) In which of the following categories does this person fit:

1. spouse?
2. parent?
3. sibling?
4. child?
5. other relative?
6. boyfriend/girlfriend?
7. friend?
8. neighbour?
9. acquaintance?
10. helping professional?
11. other (SPECIFY) _____
99. no response/don't know

(c) How many times in an average month do you talk face-to-face with this person?

1. daily
2. more than once per week
3. once per week
4. two or three times per month
5. once per month or less
6. never
9. no response/don't know

SECTION 10: LIFE EVENTS

83. I would like to know about some of the major events that may have taken place in your immediate family during the past year. I would also like to know if the occurrence of these events was stressful to you. As I read through the list of events please tell me which ones happened to you or to a member of your immediate family during the past year. For any that have occurred could you also tell me which statement on this card best describes how stressful you found it personally.

INTERVIEWER: HAND RESPONDENT PALE PINK CARD

1. very stressful
2. somewhat stressful
3. not at all stressful
9. no response/don't know

	Yes	No	nr/ dk	stress value
a) had a baby	1	2	9	—
b) stopped formal schooling	1	2	9	—
c) got married	1	2	9	—
d) changed to a different line of work or started working	1	2	9	—
e) lost a job	1	2	9	—
f) retired	1	2	9	—
g) been unemployed	1	2	9	—
h) had other business or work related difficulties	1	2	9	—
i) death of a close family member	1	2	9	—
j) death of a close friend	1	2	9	—
k) had a period of financial difficulty	1	2	9	—
l) had difficulties with your boss	1	2	9	—
m) been divorced or separated	1	2	9	—
n) had a son or daughter leave home	1	2	9	—
o) moved to a different house, apartment or community	1	2	9	—
p) experienced serious personal injury or illness other than just your major limiting health conditions	1	2	9	—
q) had trouble with your in-laws	1	2	9	—
r) family member experienced serious personal injury or illness	1	2	9	—
s) relations with parents changed for the worse	1	2	9	—
t) conflict with the law	1	2	9	—
u) other (SPECIFY) _____	1	2	9	—

INTERVIEWER: TAKE BACK PALE PINK CARD

SECTION 11: SELF CARE AND ACTIVITIES OF DAILY LIVING

84. There are many activities that form a part of our daily lives that may cause some difficulties for individuals with physical limitations. I would like to know if you have any problems with these activities. For each activity I read, please choose the answer that best describes your level of performance. Use the scale on this card to tell me how easily you can do each activity.

INTERVIEWER: HAND RESPONDENT BUFF CARD

	LEVEL OF DIFFICULTY							
	1. easily 2. with difficulty but without help 3. with special equipment but no help 4. with help from someone 5. completely unable to do this 9. no response/don't know/never does							
a) are you able to feed yourself	1	2	3	4	5	6	9	
b) are you able to dress yourself	1	2	3	4	5	6	9	
c) are you able to use the toilet	1	2	3	4	5	6	9	
d) are you able to bathe yourself	1	2	3	4	5	6	9	
e) are you able to brush and comb your hair (for men - ask about shaving)	1	2	3	4	5	6	9	
f) are you able to move in and out of bed, chair	1	2	3	4	5	6	9	
g) are you able to walk	1	2	3	4	5	6	9	

	LEVEL OF DIFFICULTY							
	1. easily 2. with difficulty but without help 3. with special equipment but no help 4. with help from someone 5. completely unable to do this 9. no response/don't know/never does							
h) are you able to walk upstairs	1	2	3	4	5	6	9	
i) are you able to climb downstairs	1	2	3	4	5	6	9	
j) are you able to drive a car	1	2	3	4	5	6	9	
k) are you able to use public transportation	1	2	3	4	5	6	9	
l) are you able to go shopping	1	2	3	4	5	6	9	
m) are you able to cook a meal	1	2	3	4	5	6	9	
n) are you able to do light cleaning,dusting,sweeping	1	2	3	4	5	6	9	
o) are you able to do laundry	1	2	3	4	5	6	9	

INTERVIEWER: TAKE BACK BUFF CARD

FOR PEOPLE WHO NEED HELP WITH OR CANNOT DO SOME ACTIVITIES OF DAILY LIVING:

85. When you do need help to do any of these activities, do you get assistance from: CIRCLE AS MANY AS APPLY

1. family members?
2. friends and neighbours?
3. agency worker, home care help that you do not pay for?
4. people you hire yourself?
9. no response/don't know

IF PERSON GETS HELP FROM AGENCY WORKERS:

a) What agency (agencies) do you get help from?

1. _____
2. _____
3. _____
4. _____
9. no response/don't know

b) Thinking about the help you get from the agency (agencies) would you say it is:

1. excellent help - it meets all or most of your needs?
2. adequate help - it meets many of your needs?
3. not very good help - it does not meet many of your needs?
9. no response/don't know

IF PERSON HIRES OWN HELP:

86. Do you hire your own help because:

1. you are not eligible for any help from an agency?
2. you need more help than any agency can or does provide you?
3. you prefer private help?
4. other (SPECIFY) _____
9. no response/don't know

SECTION 12: USE OF AND NEED FOR REHABILITATION SERVICES

87. Are you currently taking any medication for your limiting health condition?

1. yes
2. no
9. no response/don't know

IF YES: ASK WHAT MEDICATIONS AND HOW OFTEN THEY TAKE THEM:

	<u>Medication</u>	<u>Nr/Dk</u>	<u>How Often</u>	<u>Nr/Dk</u>
1.	_____	9	_____	9
2.	_____	9	_____	9
3.	_____	9	_____	9
4.	_____	9	_____	9
5.	_____	9	_____	9
6.	_____	9	_____	9
7.	_____	9	_____	9
8.	_____	9	_____	9

88. In what year did you first receive treatment, including medication, for your limiting health condition?

_____ (year)

9. no response/don't know

89. How often do you go to your physician for routine checkups of your major limiting health condition?

1. once a month or more
2. less than once a month
3. once a year
4. less than once a year
9. no response/don't know

90. Not counting checkups with your physician, are you presently involved in a treatment program on a regular or routine basis (not including medication taken on a routine basis)?

1. yes
2. no
9. no response/don't know

91. Not counting checkups with your physician, how often do you usually receive treatment, other than medication?

1. more than once a week
2. once a week
3. once every two weeks
4. once a month
5. several times a year
6. once a year
7. less than once a year
8. never
9. no response/don't know

92. When you do receive treatment, including medication, is this because:
CIRCLE AS MANY AS APPLY

1. a problem comes up?
2. new treatments become available?
3. you want more treatment to improve your condition?
4. you need treatment to maintain your present level of performance or health?
5. other (SPECIFY) _____
9. no response/don't know

93. When was the last time you received treatment, including medication?

1. currently receiving treatment or medication - GO TO QUESTION 95
2. within the last one year - GO TO QUESTION 95
3. one to five years ago
4. more than five years ago
9. no response/don't know

IF NO TREATMENT OR MEDICATION WITHIN THE LAST ONE YEAR:

94. Could you tell me why you have not had any treatment in the past year?
Is it because:

1. you do not require any treatment?
2. your condition does not benefit from treatment?
3. you are not eligible for any treatment programs?
4. it is too expensive?
5. no suitable program is available?
6. it is too difficult to get there?
7. there is too long a waiting list?
8. other (SPECIFY) _____
9. no response/don't know

95. Now I would like to know which of the following treatments or services you are now receiving or have had in the last five years for any of your limiting health conditions.

CIRCLE AS MANY AS APPLY

Have you had:

	<u>Yes</u>	<u>No</u>	<u>Don't Know</u> <u>No response</u>
1) medical care from a physician *	1	2	9
2) chiropractic care	1	2	9
3) speech therapy	1	2	9
4) physiotherapy	1	2	9
5) occupational therapy	1	2	9
6) rehabilitation counselling	1	2	9
7) home nursing care	1	2	9
8) homemaker service	1	2	9
9) social worker service	1	2	9
10) fitting with prosthesis, braces, wheelchair, orthopedic footwear	1	2	9
11) nutrition - diet counselling	1	2	9
12) general exercise classes, swimming for handicapped	1	2	9
13) spiritual healer	1	2	9
14) masseuse	1	2	9
15) reflexologist	1	2	9
16) other (SPECIFY) _____	1	2	9
17) other (SPECIFY) _____	1	2	9

96. Which one of the treatments or services you received in the last five years was of most benefit to you? CIRCLE ONE ONLY. THIS MUST BE A TREATMENT/SERVICE PREVIOUSLY CHOSEN IN QUESTION 95.

- 1) medical care from a physician
- 2) chiropractic care
- 3) speech therapy
- 4) physiotherapy
- 5) occupational therapy
- 6) rehabilitation counselling
- 7) home nursing care
- 8) homemaker service
- 9) social worker service
- 10) fitting with prosthesis, braces, wheelchair, orthopedic footwear
- 11) nutrition-diet counselling
- 12) general exercise classes, swimming for handicapped
- 13) spiritual healer
- 14) masseuse
- 15) reflexologist
- 16) no treatments or services in the last five years
- 17) other (SPECIFY) _____

18) other (SPECIFY) _____

99) no response/don't know _____

97. Have you ever had a surgical operation for your major limiting health problem?

1. yes
2. no - GO TO QUESTION 99
9. no response/don't know

IF YES: How many times have you had surgery for this condition?

_____ times

9. no response/don't know

IF YES: When was your most recent operation for this condition?

_____ year

9. no response/don't know

98. Do you expect to have further surgery for this condition?

1. yes
2. no
9. no response/don't know

IF PERSON HAS MORE THAN ONE LIMITING HEALTH CONDITION

99. Have you ever had surgery for your other limiting health condition(s)?

1. yes
2. no
9. no response/don't know

IF YES:

- a) For which condition(s) was this?
- b) How many times have you had surgery for this condition?
- c) When was your most recent operation for this condition?

INTERVIEWER: USE 9 TO INDICATE NO RESPONSE/DON'T KNOW

CONDITION	NUMBER TIMES SURGERY	DATE OF MOST RECENT OPERATION

FOR ALL RESPONDENTS

100. Rehabilitation services can be offered in a variety of settings. If you needed any rehabilitation services in which of the following settings would you prefer to receive it?

1. in a Rehabilitation Centre where services and treatment programs for all different kinds of conditions are available
2. in a centre with service and treatment programs only for people with similar kinds of limitations
3. hospital in-patient and out-patient clinics
4. other (SPECIFY) _____
9. no response/don't know

101. Have you ever needed any special equipment (e.g. wheelchair, artificial limb, hearing aids, dentures, braces, glasses)?

1. yes
2. no
9. no response/don't know

IF YES Have you ever been unable to get any equipment you have needed?

1. yes
2. no - GO TO QUESTION 102
9. no response/don't know

IF YES: Is this because: CIRCLE AS MANY AS APPLY

1. you could not afford the equipment?
2. it was not available - no place to buy it, no one makes it?
3. you would have to remodel your house in order to use this equipment?
4. you didn't know where to buy it?
5. you didn't want to use it or be bothered with it?
6. other (SPECIFY) _____
9. no response/don't know

102. Is there a physician who provides your routine medical care for your limiting health condition?

1. in your community
2. within an hour's drive
3. more than an hour's drive away
9. no response/don't know

103. When you need more specialized treatment for your condition is treatment available?

1. in your community
2. within an hour's drive
3. more than an hour's drive away
4. do not need more specialized treatment
9. no response/don't know

104. When you think of your health condition and its influence on your life expectancy do you think your life expectancy is?

1. the same as if you did not have the health problem
2. five to ten years shorter than it would be if you did not have the condition
3. more than ten years shorter than it would be if you did not have the condition
4. not more than five years from now
9. no response/don't know

105. Now I would like to ask you how you feel about the people who provide treatment and about treatment itself. For each statement I read please use the scale on this card to tell me the number of the category that describes how strongly you agree or disagree with each statement.

1. strongly agree
2. mildly agree
3. neither agree nor disagree
4. mildly disagree
5. strongly disagree
9. no response/don't know

INTERVIEWER: HAND RESPONDENT DARK BLUE CARD

- | | | | | | | |
|---|---|---|---|---|---|---|
| a) It doesn't matter what treatment I get because not much can be done about my condition. | 1 | 2 | 3 | 4 | 5 | 9 |
| b) Most of the people who treat me take a personal interest in how I'm doing. | 1 | 2 | 3 | 4 | 5 | 9 |
| c) Doctors and other professionals don't teach me the things I really need to know to deal with my condition. | 1 | 2 | 3 | 4 | 5 | 9 |
| d) First rate rehabilitation services could make a real difference for people with my condition. | 1 | 2 | 3 | 4 | 5 | 9 |
| e) Doctors and other people who treat me don't understand how I really feel. | 1 | 2 | 3 | 4 | 5 | 9 |
| f) Treatment available for my condition is often more trouble than it is worth. | 1 | 2 | 3 | 4 | 5 | 9 |
| g) Most people who provide treatment would prefer to spend their time with other kinds of patients. | 1 | 2 | 3 | 4 | 5 | 9 |

INTERVIEWER: TAKE BACK DARK BLUE CARD

SECTION 13: SOCIAL SUPPORT

106. We would like to know your thoughts and feelings about yourself and the people who matter to you. After reading each item, please check the box below that best applies to you.

Ronnie

Stuart

Peter

- a. People are devoted to Ronnie and love him. They always support him, listen to him and sympathize with him. They care about him a lot.
- People are usually fond of Stuart. They can be sympathetic, but do not always listen to him nor support him.
- People are not devoted to Peter. They do not support him, listen to him or sympathize with him. They do not care about him or love him.

Check one box.

☐☐☐☐☐I'm like
RonnieI'm halfway
between Ronnie
and StuartI'm like
StuartI'm halfway
between Stuart
and PeterI'm
like
Peter

John

David

Andy

- b. People rarely let John know that he is wanted. He does not really make a difference to them and they are rarely concerned about him. He does not matter to them.
- People sometimes let David know that he matters. Sometimes they think that he makes a difference to them.
- People constantly let Andy know that he is wanted. He really makes a difference to them. They are concerned about him and he matters.

Check one box.

☐☐☐☐☐I'm like
JohnI'm halfway
between John
and DavidI'm like
DavidI'm halfway
between David
and AndyI'm like
Andy

Jonathon

Bill

Allen

- c. People always think that Jonathon is a friend. They like talking with him and spending a lot of time with him. He always has lots of people around. He is seldom alone.

Bill has friends and is a good person to be with, but he isn't always surrounded by people.

Allen is mostly alone. He rarely sees people or spends time with them. He is most often by himself.

Check one box.

☐☐☐☐☐

I'm like
Jonathon

I'm halfway
between Jonathon
and Bill

I'm like
Bill

I'm halfway
between Bill
and Allen

I'm
like
Allen

Steve

Gregory

Charles

- d. Steve rarely has a close friend that he can count on. He does not know that they will always be there for him to lean on and he does not support them.

Gregory sometimes has a close friend who is there for him and who he can count on.

Charles always has a close friend that he can count on. He does not have to worry about whether they will be there for him to lean on. He gives them the same support.

Check one box.

☐☐☐☐☐

I'm like
Steve

I'm halfway
between Steve
and Gregory

I'm like
Gregory

I'm halfway
between Gregory
and Charles

I'm like
Charles

Dennis

Brian

Edward

- e. People believe that Dennis will make the right decisions and do the right things. They have confidence and faith in him.

Some people have confidence and faith in Brian. Sometimes they think that he will make the right decisions and do the right things.

People rarely believe that Edward will make the right decisions or do the right things. They hardly ever have confidence in him.

Check one box.

☐
☐
☐
☐
☐

I'm like
Dennis

I'm halfway
between Dennis
and Brian

I'm like
Brian

I'm halfway
between Brian
and Edward

I'm
like
Edward

Ronnie

Richard

Jeffery

- f. Ronnie rarely spends time with other people. When he wants to do things, he hardly ever has anyone to do things with him.

Richard sometimes spends time with other people. When he wants to do things, sometimes there are other people around to do things with him.

Jeffery is almost always with other people. Whenever he wants to do things, he knows that one or another of his friends will be there to do things with him.

Check one box.

☐
☐
☐
☐
☐

I'm like
Ronnie

I'm halfway
between Ronnie
and Richard

I'm like
Richard

I'm halfway
between Richard
and Jeffery

I'm like
Jeffery

- | | Hank | Michael | Anthony |
|----|--|--|---|
| g. | Hank knows that people care a lot about him. He has their attention and support. | Michael sometimes has people's attention and support. He sometimes feels that they care about him. | Anthony is uncertain that people care about him. He gets little attention or support. |

Check one box.

<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I'm like Hank	I'm halfway between Hank and Michael	I'm like Michael	I'm halfway between Michael and Anthony	I'm like Anthony

- | | Patrick | Gordon | Joel |
|----|---|---|---|
| h. | Patrick is rarely admired and praised. There are very few people who think Patrick is important and worthy. | Gordon is sometimes admired and praised by some people. He is not always being reminded of his worth. | Joel is constantly being admired by people. They always praise him and think that he is important and worthy. |

Check one box.

<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I'm like Patrick	I'm halfway between Patrick and Gordon	I'm like Gordon	I'm halfway between Gordon and Joel	I'm like Joel

Ricky

Harold

Jason

1. Ricky does not have a lot different people to lean on. He does not belong to a group of people who know each other and who would help one another when needed.

Harold sometimes has people he can lean on. He belongs to a group of people who sometimes help one another when needed.

Jason knows that there are a lot of different people he can lean on. He belongs to a group of many people who know each other and who always help one another out when needed.

Check one box.

☐☐☐☐☐

I'm like
Ricky

I'm halfway
between Ricky
and Harold

I'm like
Harold

I'm halfway
between Harold
and Jason

I'm
like
Jason

Household I.D.	_____
County	_____
F. E. D.	_____
E. A.	_____
AREA	_____

STUDY OF PHYSICAL HEALTH PROBLEMS

SCREENING INTERVIEW

Respondent's Address: _____

Record of Contacts			
Contact No.	Date		Comments
	Day	Month	
1			
2			
3			
4			

HOUSEHOLD I.D. NUMBER _____

Hello, my name is _____. I represent the Health Care Research Unit at The University of Western Ontario. We are conducting a health survey in this area and your house was selected to be part of this survey by a random sampling procedure. Could you spare a few moments to answer some brief questions? Your responses will be held in the strictest confidence.

1. How many adults live in your household altogether? _____

Please include boarders and roomers, as well as members of your family.

2. Could you tell me the age and sex of each adult?

	Age	Male	Female
a) person 1	_____	1	2
b) person 2	_____	1	2
c) person 3	_____	1	2
d) person 4	_____	1	2

IF TALKING TO SOMEONE WHO IS NOT VISIBLY DISABLED

3. Do any adults in the household have any physical health condition or physical handicap that has resulted in a change in their daily routine or that limits the kind of or amount of activity they can carry out? (For instance: work, housework, school, play recreation, shopping or participation in social activities or community activities).

1. yes - GO TO QUESTION 6
2. no - TERMINATE INTERVIEW
3. refused to answer - TERMINATE INTERVIEW

TERMINATE: That's all the questions I have for you. Thank you very much for your participation in this survey.

IF TALKING TO SOMEONE WHO IS VISIBLY DISABLED

4. We are doing a survey on physical health conditions or problems that in some way limit an individual's functioning. We are interested in learning something about the ways it affects peoples lives and how they cope.

Would you be interested in participating in our study? It will take about one hour to complete the interview and this can be at a time convenient to you:

1. yes, I agree to participate.
2. no, I refuse to participate.

IF NO: I understand if you do not want to participate in the hour long interview. But, could you please answer a few more short questions.

5. Is there anyone else living here who has a physical health condition that has resulted in a change in their daily routine or that limits the kind of or amount of activity they can carry out? (For instance: work, housework, school, play, recreation, shopping, or participation in normal activities or community activities).

1. yes - GO TO QUESTION 6
2. no - GO TO QUESTION 7
9. don't know/no response

6. How many persons have such a condition?

IF TALKING TO PERSON WITH HEALTH PROBLEM:

7. Could you tell me your age? (COMPLETE CHART BELOW)

IF NOT TALKING TO PERSON WITH HEALTH PROBLEM:

Could you tell me the age and sex of this person (these persons)?

	Age	Male	Female
a) person 1	_____	1	2
b) person 2	_____	1	2
c) person 3	_____	1	2
d) person 4	_____	1	2

8. Would you mind telling me a little about each condition and how long you (this person) (these persons) have been affected by it?

	<u>CONDITION</u>	<u>HOW LONG</u>
a) person 1		
b) person 2		
c) person 3		
d) person 4		

IF PERSON HAS BEEN AFFECTED BY A CONDITION FOR LESS THAN THREE MONTHS:

9. Is it expected that this condition will be permanent or long standing, that is, will it last for more than three months?

	<u>Yes</u>	<u>No</u>	<u>Don't know/ no response</u>
a) person 1	1	2	9
b) person 2	1	2	9
c) person 3	1	2	9
d) person 4	1	2	9

INTERVIEWER: TERMINATE INTERVIEW FOR ANYONE WHO DOES NOT HAVE ANY CONDITION THAT WILL LAST LONGER THAN THREE MONTHS.

TERMINATE: That's all the questions I have for you. Thank you for your participation in this survey.

I would like very much to meet with this person (these persons) (you) to discuss problems he or she (you) may experience because of his or her (your) physical health problems, and the kinds of feelings that he or she (you) may have about the health problems. It will take about an hour to complete the interview.

10. (Are you) is this person available for an interview now or can we arrange to make an appointment for a more convenient time. If you cannot arrange an appointment for this person, could I have your phone number so I could call and speak to him or her personally?

COMPLETE CHART

1. available now
2. appointment made
3. will telephone to arrange appointment
9. refused to participate

Name	Phone Number	Date and Time

FOR EACH ADDITIONAL DISABLED PERSON:

Perhaps we can also arrange a schedule of appointments so that I can meet with each of the individuals with a limiting condition for an interview. Or if you cannot arrange an appointment for them, I can call and speak to them personally.

COMPLETE CHART

1. available now
2. appointment made
3. will telephone to arrange appointment
9. refused to participate

SECTION 4: COPING

People use many different ways to handle stressful or upsetting situations they experience. I would like to know how you deal with upsetting situations that may occur because of your physical health problems. I am interested in knowing how you handled upsetting situations that you have either completely settled, that you have learned to put up with, or that are still ongoing and troublesome for you.

33. a) First, I would like to know if you have experienced any upsetting or stressful situations because of your physical health problems, in the last year. Again this could be situations you have either resolved, have learned to accept, or are still dealing with.

1. yes
2. no - GO TO QUESTION 35
9. no response/don't know

IF YES: Could you please tell me a little about one of the most upsetting situations you encountered?

ASK WHAT HAPPENED, WHO WAS INVOLVED, WHAT MADE IT STRESSFUL.

- b) Thinking about this situation, would you say it:

1. has been completely settled?
2. is a situation you have learned to accept?
3. is still ongoing and upsetting for you?
9. no response/don't know

- c) Now I would like to know how stressful you found this situation. On a scale ranging from 1 to 7, with 7 being very stressful and 1 being mildly stressful, how would you rate the stress of this situation?
Please pick the number on this scale that best describes how stressful this was for you.

INTERVIEWER: HAND RESPONDENT WHITE CARD

1	2	3	4	5	6	7
mildly stressful			moderately stressful			very stressful

- d) Now I would like to know what you did or are doing about this situation. For each of the following statements, please indicate how often you used each thought or behaviour to deal with the situation. Please use the scale on this card to tell me the number of the response category that best describes how often you used each of these.

INTERVIEWER: HAND RESPONDENT BRIGHT PINK CARD

Did you:	<u>very often</u>	<u>some- what often</u>	<u>not very often</u>	<u>never</u>	<u>nr/ dk</u>
a) bargain or compromise to get something good from the situation?	1	2	3	4	9
b) turn to a friend or relative for advice?	1	2	3	4	9
c) accept the situation because there was nothing you could do about it?	1	2	3	4	9
d) go on as if nothing had happened?	1	2	3	4	9
e) keep yourself busy with other things?	1	2	3	4	9
f) try not to get too serious about it - laugh it off?	1	2	3	4	9
g) remind yourself that things could be a lot worse?	1	2	3	4	9
h) do something that you didn't think would help but at least you were doing something?	1	2	3	4	9
i) not let on to anyone how bad things were?	1	2	3	4	9
j) come up with a couple of different solutions to the problem?	1	2	3	4	9
k) get professional help and do what was recommended?	1	2	3	4	9

	<u>very</u> <u>often</u>	<u>some-</u> <u>what</u> <u>often</u>	<u>not</u> <u>very</u> <u>often</u>	<u>never</u>	<u>nr/</u> <u>dk</u>
l) concentrate on something good that could come out of the whole thing - look for the silver lining?	1	2	3	4	9
m) tell yourself things that helped you to feel better?	1	2	3	4	9
n) take your problems out on other people?	1	2	3	4	9
o) feel that time would make a difference - the only thing to do was wait?	1	2	3	4	9
p) make a plan of action and follow it?	1	2	3	4	9
q) try to forget it - put it out of your mind?	1	2	3	4	9
r) let your feelings out somehow?	1	2	3	4	9
s) sit down and talk things out with the other people involved?	1	2	3	4	9
t) remind yourself that you were a lot better off than some people?	1	2	3	4	9

34. a) Did you experience any other upsetting situations in the last year that were related to your physical health problems? Again, this could be a situation that now may be completely settled, or that you have grown to accept, as well as a situation that you still find troublesome.

1. yes
2. no - GO TO QUESTION 35
9. no response/don't know

IF YES: Could you please tell me a little about one of these stressful situations?

ASK WHAT HAPPENED, WHO WAS INVOLVED, WHAT MADE IT STRESSFUL.

- b) Thinking about this situation would you say it:

1. has been completely settled?
2. is a situation you have learned to accept?
3. is still ongoing and upsetting for you?
9. no response/don't know

- c) Now I would like to know how stressful you found this situation. On a scale ranging from 1 to 7, with 7 being very stressful and 1 being mildly stressful, how would you rate the stress of this situation? Please pick the number on this scale that best describes how stressful this was for you.

1	2	3	4	5	6	7
mildly stressful			moderately stressful			very stressful

INTERVIEWER: TAKE BACK WHITE CARD

- d) Now I would like to know what you did or are doing about this situation. I want you to go through the same list as before and tell me how often you used these thoughts and behaviours.

Did you:

	very often	some- what often	not very often	never	nr/ dk
a) bargain or compromise to get something good from the situation?	1	2	3	4	9
b) turn to a friend or relative for advice?	1	2	3	4	9
c) accept the situation because there was nothing you could do about it?	1	2	3	4	9
d) go on as if nothing had happened?	1	2	3	4	9
e) keep yourself busy with other things?	1	2	3	4	9
f) try not to get too serious about it - laugh it off?	1	2	3	4	9
g) remind yourself that things could be a lot worse?	1	2	3	4	9
h) do something that you didn't think would help but at least you were doing something?	1	2	3	4	9
i) not let on to anyone how bad things were?	1	2	3	4	9
j) come up with a couple of different solutions to the problem?	1	2	3	4	9

	<u>very often</u>	<u>some- what often</u>	<u>not very often</u>	<u>never</u>	<u>nr/ dk</u>
k) get professional help and do what was recommended?	1	2	3	4	9
l) concentrate on something good that could come out of the whole thing - look for the silver lining?	1	2	3	4	9
m) tell yourself things that helped you to feel better?	1	2	3	4	9
n) take your problems out on other people?	1	2	3	4	9
o) feel that time would make a difference - the only thing to do was wait?	1	2	3	4	9
p) make a plan of action and follow it?	1	2	3	4	9
q) try to forget it - put it out of your mind?	1	2	3	4	9
r) let your feelings out somehow?	1	2	3	4	9
s) sit down and talk things out with the other people involved?	1	2	3	4	9
t) remind yourself that you were a lot better off than some people?	1	2	3	4	9

INTERVIEWER: TAKE BACK BRIGHT PINK CARD

APPENDIX B

LETTERS OF INFORMATION



The University of Western Ontario

Health Care Research Unit
First Floor, C.F.C. Building
London, Canada
N6A 5B8

The Health Care Research Unit at The University of Western Ontario is conducting a research project on the physical health problems of residents of Southwestern Ontario. Your household has been randomly selected from a list of all Southwestern Ontario households. Your participation in this study will greatly contribute to our understanding of the needs of people with physical health problems and to our ability to meet these needs.

Your participation will involve an interview in your home with a member of the project staff. The interview can be arranged at a time convenient for you and it will take approximately one hour to complete. Several topics will be covered during the interview including your health problems, how you feel about them and how they affect your life. There are also questions about your relationships with others, as well as several items of descriptive information.

All information obtained will be kept in the strictest confidence. Questionnaires will be identified by means of a unique number and no personal information that will lead to the identity of any individual respondent will remain on the questionnaire. The list of names and identification numbers will be kept locked with access limited to the project staff. In this way, anonymity will be assured.

Your participation in this study, is of course, entirely voluntary. We would like to point out, however, that there is a pressing need for research on the needs of people with physical health problems. By taking the time for an interview, you will be making an important contribution to one study in this area.

We would very much appreciate your participation in this study. If you are unable to be interviewed at this time, one of the members of the project team will call you soon to arrange a convenient time for the interview. If you have any questions or would like further information you may call Ms. Deborah Levin at the Health Care Research Unit (519) 679-6760. If you live outside the City of London, please call collect.

Sincerely,

Deborah Levin
Project Director
Study of Physical Health Problems



The University of Western Ontario

Health Care Research Unit
First Floor, C.F.C. Building
London, Canada
N6A 5B8

September 22, 1981

You may recall that some time ago an interviewer from the Health Care Research Unit came to your house and asked you to participate in an interview concerning physical health problems. At that time you chose not to participate in the study.

Participation in the study is, of course, completely voluntary. While we fully respect your right to decline, we wonder whether you would be willing to reconsider your decision not to participate. There is a pressing need for research on the needs of people with physical health problems. By taking the time for an interview, you will be making an important contribution to one study in this area.

The interview takes approximately one and a half hours to complete. Several topics will be covered in the interview, including your health problems, how you feel about them, and how they affect your life.

All information obtained will be kept in the strictest confidence, and once the interview has been returned to the office, it will be identified by a unique number and no personal information will lead to the identity of any individual respondent.

.....2.....

To find out whether or not you have changed your mind about participating in the study, an interviewer will be telephoning you shortly. Should you wish to participate, you can arrange then for an interview at a time convenient to you.

We would very much appreciate your participation in this study. If you have any further questions or would like further information you may call Ms. Deborah Levin at the Health Care Research Unit, (519) 679-6760.

Sincerely,

Deborah Levin
Project Director
Study of Physical Health Problems

DL:kl

APPENDIX C

ADDITIONAL TABLES

Table C.1

TEST OF HYPOTHESIS OF COMMON POPULATION CORRELATION
AND ESTIMATION OF POPULATION CORRELATION

$$\chi^2 = \sum (n-3)Z_i^2 - [\sum (n-3)Z_i]^2 / \sum (n-3)$$

1) PSR Scale with the CES-D Scale	6) Revised Kaplan Scale with Self-Esteem
$\chi^2 = 13.896$	$\chi^2 = 2.841$
d.f. = 8	d.f. = 8
p > .05	p > .05
2) Revised Kaplan Scale with CES-D Scale	7) Coping with the CES-D Scale
$\chi^2 = 10.713$	$\chi^2 = 6.178$
d.f. = 8	d.f. = 8
p > .05	p > .05
3) PSR Scale with General Distress	8) Coping with General Distress
$\chi^2 = 12.978$	$\chi^2 = 5.091$
d.f. = 8	d.f. = 8
p > .05	p > .05
4) Revised Kaplan Scale with General Distress	9) Coping with Self-Esteem
$\chi^2 = 8.834$	$\chi^2 = 1.102$
d.f. = 8	d.f. = 8
p > .05	p > .05
5) PSR Scale with Self-Esteem	
$\chi^2 = 12.09$	
d.f. = 8	
p < .05	

Table C.2

AGE DISTRIBUTION OF THE SAMPLE

	NUMBER	PERCENTAGE
18 - 29 years	76	7.7
30 - 39 years	110	11.1
40 - 49 years	122	12.3
50 - 59 years	192	19.5
60 - 69 years	269	27.2
70 - years and over	220	22.2
TOTAL	989	100.0

Table C.3

MARITAL STATUS DISTRIBUTION OF THE SAMPLE

	NUMBER	PERCENTAGE
Single/never married	98	9.9
Married/common law	642	65.0
Separated/divorced	82	8.3
Widowed	166	16.8
TOTAL	988	100.0

Table C.4

DISTRIBUTION OF THE SAMPLE ON HOUSEHOLD INCOME

	NUMBER	PERCENTAGE
under \$ 5,000	123	13.7
\$ 5,000 - \$ 9,999	228	25.4
\$10,000 - \$14,999	175	19.5
\$15,000 - \$24,999	200	22.3
\$25,000 - \$34,999	99	11.0
\$35,000 - \$44,999	43	4.8
\$45,000 and over	29	3.2
TOTAL	897	100.0

Table C.5

DISTRIBUTION OF THE SAMPLE ON LEVEL OF EDUCATION

	NUMBER	PERCENTAGE
0 - 8 years	376	38.3
9 - 10 years	222	22.3
11 - 13 years	320	32.3
University (one or more years)	71	7.1
TOTAL	986	100.0

Table C.6

DISTRIBUTION OF THE SAMPLE ON CURRENT EMPLOYMENT STATUS

	NUMBER	PERCENTAGE
Employed full-time	165	16.7
Employed part-time	85	8.6
Unemployed	184	18.6
Homemaker	242	24.5
Retired	280	28.3
Sick Leave	20	2.0
Student	12	1.2
TOTAL	988	100.0

Table C.7

DISTRIBUTION OF DISABILITY GROUPS WITHIN AGE AND SEX CATEGORIES

DISABILITY GROUP	BOTH SEXES					MALES					FEMALES				
	Age					Age					Age				
	18-49	50-64	65+	total		18-49	50-64	65+	total		18-49	50-64	65+	total	
Neoplasms	N 6 % 23.1	11 42.3	9 34.6	26 100.0		4 21.1	7 36.8	8 42.1	19 73.1		2 28.6	4 57.1	1 14.3	7 26.9	
Endocrine, metabolic, blood and genitourinary problems	N 10 % 27.8	13 36.1	13 36.1	36 100.0		1 9.1	4 36.4	6 54.5	11 30.6		9 36.0	9 36.0	7 28.0	25 69.4	
Nervous system	N 45 % 57.0	17 21.5	17 21.5	79 100.0		22 59.5	8 21.6	7 18.9	37 46.8		23 54.8	9 21.4	10 23.8	42 53.2	
Circulatory system	N 21 % 9.1	98 42.4	112 48.5	231 100.0		11 8.5	59 45.4	60 46.2	130 56.3		10 9.9	39 38.6	52 51.5	101 43.7	
Respiratory system	N 25 % 32.1	27 34.6	26 33.3	78 100.0		5 13.5	15 40.5	17 45.9	37 47.4		20 48.8	12 29.3	9 22.0	41 52.6	
Digestive system	N 5 % 25.0	8 40.0	7 35.0	20 100.0		2 33.3	4 66.7	0 0	6 30.0		3 21.4	4 28.6	7 50.0	14 70.0	
Skin and musculo-skeletal disorders	N 134 % 35.3	124 32.6	122 32.1	380 100.0		60 41.4	46 31.7	39 26.9	145 38.2		74 31.5	78 33.2	83 35.3	235 61.8	
Fractures and trauma	N 29 % 54.7	13 24.5	11 20.8	53 100.0		19 57.6	10 30.3	4 12.1	33 62.3		10 50.0	3 15.0	7 35.0	20 37.7	
Deformities	N 31 % 37.3	22 26.5	30 36.1	83 100.0		12 33.3	12 33.3	12 33.3	36 43.4		19 40.4	10 21.3	18 38.3	47 56.6	

Table C.8

DISTRIBUTION OF THE SAMPLE ON ACTIVITY LIMITATIONS
DUE TO DISABLING CONDITION

	NUMBER	PERCENTAGE
Very much limited	635	64.3
Somewhat limited	288	29.1
Not very much limited	65	6.6
TOTAL	988	100.0

Table C.9

DISTRIBUTION OF THE SAMPLE ON PERCEIVED SEVERITY
OF DISABLING CONDITION

	NUMBER	PERCENTAGE
Very severe	223	22.7
Severe	320	32.6
Somewhat severe	325	33.1
Not very severe	96	9.8
Not at all severe	17	1.7
TOTAL	981	100.0

Table C.10

SAMPLE STATISTICS ON THE PSR SCALE

Possible Range of Scores	15-75
Mean	64.75
Median	66.39
Standard Deviation	8.18
Variance	66.88

Table C.11

SAMPLE STATISTICS ON THE REVISED KAPLAN SCALE

Possible Range of Scores	9-45
Mean	33.00
Median	33.44
Standard Deviation	6.68
Variance	44.57

Table C.12

SAMPLE STATISTICS ON THE GENERAL DISTRESS MEASURE

Mean	-.017
Median	-.506
Standard Deviation	7.45
Variance	6.03

Table C.13

SAMPLE STATISTICS ON THE LIFE STRESS SCALE

Possible Range of Scores	0-60
Mean	7.28
Median	5.98
Standard Deviation	6.07
Variance	36.80

Table C.14

SAMPLE STATISTICS ON THE COPING INDEX

Possible Range of Scores	0-16
Mean	10.71
Median	10.93
Standard Deviation	2.75
Variance	7.58

Table C.15

SAMPLE STATISTICS ON THE CES-D SCALE

Possible Range of Scores	0-60
Mean	14.13
Median	10.64
Standard Deviation	11.54
Variance	133.25

Table C.16

Multiple Regression Analysis of the CES-D Scale
on Social Support and Selected Variables to Examine
Urban/Rural Differences

Variables	Unstandardized Regression Coefficient	Standard Error	Standardized Coefficient
Age	-.051*	.023	-.074
Sex	2.846*	1.253	.124
Perceived Severity	1.883**	.705	.157
Duration	-.087	.048	-.102
Functional Status	-.419	.282	-.079
Social Support	-2.354***	.397	-.361
D ¹	2.219	3.505	.093
D x Perceived Severity	-.351	.372	.065
D x Social Support	-.111	.059	-.032
D x Duration	-.119	1.578	.046
D x Sex	-.010	.874	-.043
D x Functional Status	.381	.471	-.014
D x Age	.000	.000	.000

R² = .265 F = 20.83 ***p ≤ .001, **p ≤ .01, *p ≤ .05 N = 706

¹ D: Urban = 0, rural = 1

Table C.17

Multiple Regression Analysis of General Distress
on Social Support and Selected Variables to Examine
Urban/Rural Differences

Variables	Unstandardized Regression Coefficient	Standard Error	Standardized Coefficient
Age	-.032***	.008	-.211
Sex	.618***	.171	.124
Perceived Severity	.230	.158	.088
Duration	-.008	.011	-.041
Functional Status	-.069	.063	-.061
Social Support	.576	.088	-.406
D	.634	.824	.123
D x Perceived Severity	-.256	.196	-.143
D x Social Support	.151	.106	.089
D x Duration	-.011	.013	-.058
D x Age	.007	.011	.087
D x Functional Status	.016	.084	.012
D x Sex	.000	.000	.000
<hr/>			
R ² = .217	F = 15.96	***p ≤ .001	N = 706

D: urban = 0, rural = 1

Table C.18

Multiple Regression Analysis of Self-Esteem on
Social Support and Selected Variables to Examine
Urban/Rural Differences

Variables	Unstandardized Regression Coefficient	Standard Error	Standardized Coefficient
Age	.023	.016	.085
Sex	-.179	.524	-.020
Perceived Severity	.380	.295	.081
Duration	.004	.020	.013
Functional Status	-.154	.118	-.074
Social Support	-.728***	.166	-.284
D ¹	.952	1.804	.102
D x Duration	-.043	.025	-.121
D x Functional Status	.206	.157	.090
D x Age	-.030	.020	-.197
D x Sex	.763	.659	.146
D x Social Support	-.152	.197	.050
D x Perceived Severity	.222	.366	.069
<hr/>			
R ² = .171	F = 10.98	***p ≤ .001	N = 706

¹ D: urban = 0, rural = 1

APPENDIX D

LOST CASES ANALYSES

1. Sex

	Completed Cases		Lost Cases	
	N	%	N	%
Males	454	45.8	260	50.8
Females	537	54.2	252	49.2
Total	991*	100.0	512*	100.0

$$\chi^2 = 3.15 \text{ (P=.08)}$$

2. Duration of Disability

	Completed Cases		Lost Cases	
	N	%	N	%
0 - 8 years	509	53.2	272	58.0
9 - 19 years	247	25.8	110	23.5
20 or more years	201	21.0	87	18.5
Total	957*	100.0	469*	100.0

$$\chi^2 = 2.96 \text{ (P=.23)}$$

*These numbers vary because complete information was not available for all cases.

3. Type of Condition

	Completed Cases		Lost Cases	
	N	%	N	%
neoplasms	28	2.9	20	4.0
endocrine, metabolic blood forming and genitourinary disorders	47	4.9	23	4.5
nervous system	109	11.1	54	10.7
circulatory system	249	25.5	156	30.8
respiratory system	73	7.4	28	5.5
digestive system	14	1.4	6	1.2
fractures and trauma	73	7.4	42	8.3
skin and musculoskeletal disorders	384	39.2	177	35.0
unspecified and ill defined disorders	2	0.2	0	0
Total	979*	100.0	506*	100.0

$$\chi^2 = 10.32 \text{ (P=.33)}$$

4. Residence

	Completed Cases		Lost Cases	
	N	%	N	%
Urban	609	61.2	347	67.5
Rural	386	38.8	167	32.5
Total	995	100.0	514	100.0

$$\chi^2 = 5.53 \text{ (P=.02)}$$

*These numbers vary because complete information was not available for all cases.

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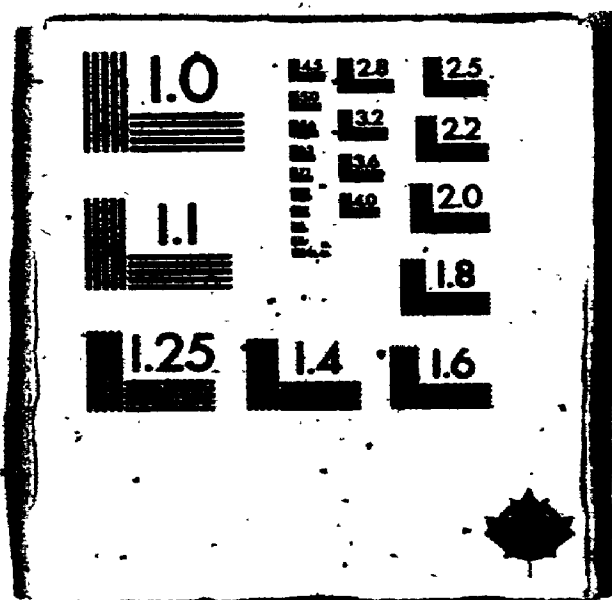
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